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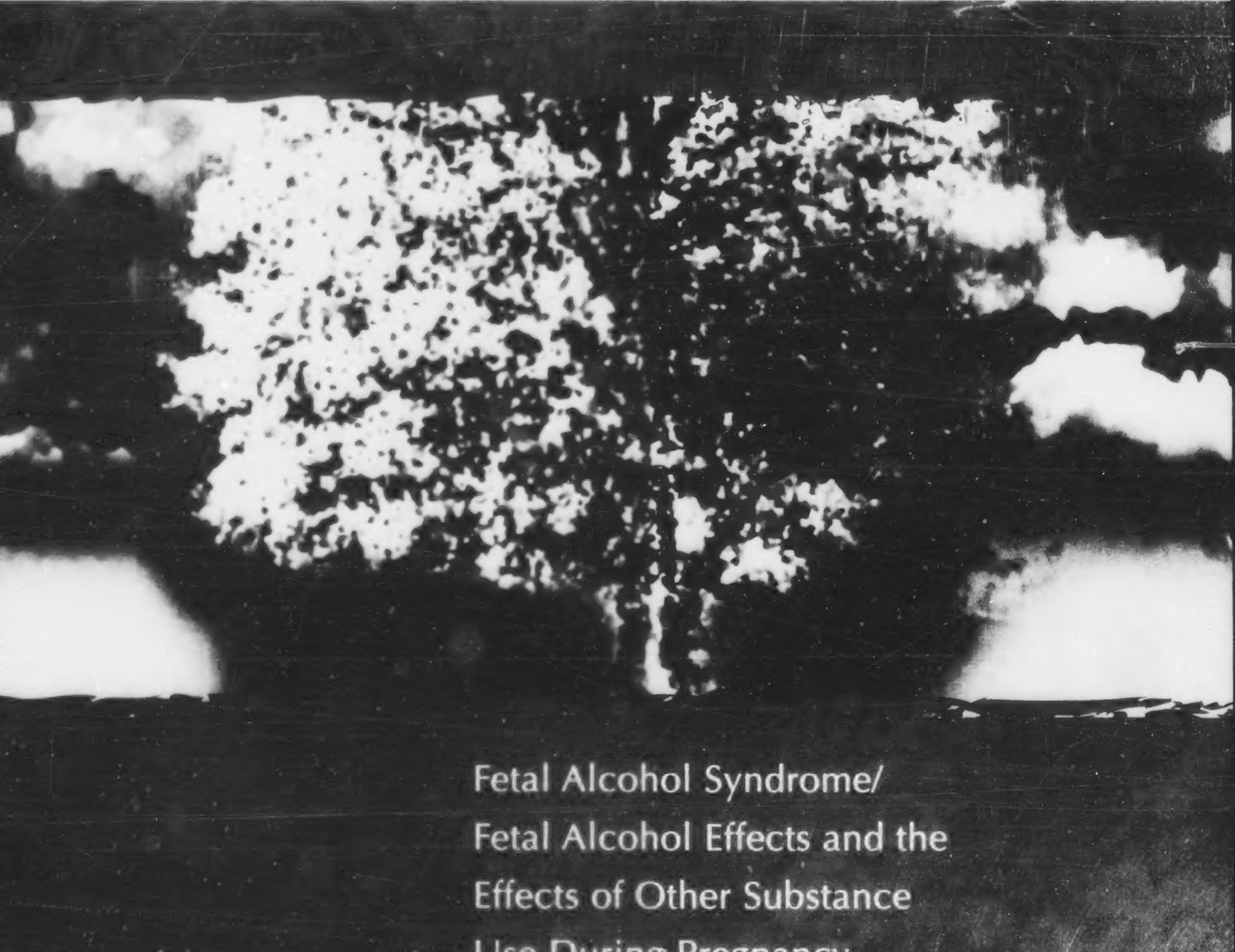

Fetal Alcohol Syndrome/ Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy

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Best Practices

Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy

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for
Canada's Drug Strategy Division
Health Canada

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Section I: Project Background and Description

1. Introduction

1.1 Project Context and Purpose

Alcohol and other substance use during pregnancy is a problem inseparable from many other issues and factors in the lives of mothers, children, their families and communities. Although Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE) and the effects from other substance use during pregnancy are preventable, solutions are complex and must be viewed from a broad-based context that requires commitment and long-term planning on the part of many (Health Canada, 1996).

The effects from alcohol use during pregnancy vary with the timing, amount and duration of alcohol consumption, the general health of the mother and the resources available. Epidemiological research into FAS/FAE is incomplete, but the associated human and economic costs are significant and lifelong, as it is a leading cause of mental disability and preventable birth defects.

The effects of other substance use during pregnancy are less well understood but thought nonetheless to be significant. These effects also vary with the manner of use, and the health and social circumstances of the mother.

In the spring of 1999, the Canadian Centre on Substance Abuse (CCSA) undertook the best practices project on fetal alcohol syndrome/fetal alcohol effects and substance use during pregnancy for Health Canada. This project was supported by a national steering committee and involved two main elements: 1) the articulation of best practices based on a literature review and 2) a situational analysis of FAS-related activity across Canada.

This literature review will identify best practices for the prevention, identification, and intervention of FAS/FAE, and the effects of other substance use during pregnancy. The specific substances other than alcohol addressed in this review are cannabis, opiates, stimulants (including cocaine), and inhalants. The review follows a life-span approach and examines the needs of different population groups.

1.2 Methodology

1.2.1 Scope of the Search

There is considerable scientific literature on the effects of alcohol and other substances during pregnancy. Although most of the literature on this issue originates in the United States, considerable attention has been given to Canadian studies. Emphasis has been given to practice-based studies that use experimental and quasi-experimental study designs. Where there is little evidence-based practice literature (e.g., interventions for adolescents and adults with FAS and related effects), reviews, consensus panel reports, and discussions and personal communications with experts have been used.

Epidemiological literature has been used to a lesser extent. As well, the literature concerning underlying mechanisms by which alcohol and other substances affect the developing fetus was beyond the scope of this review.

The CANBASE and CCSADOCS databases of the Canadian Centre on Substance Abuse (CCSA) were searched, particularly for Canadian published literature (French and English). MEDLINE, ETOH, Toxibase, and ERIC were searched for international published literature. Members of the steering committee also identified for inclusion relevant literature. Ultimately, over 500 articles were reviewed.

1.2.2 Development of Best Practice Statements

"Best practice statements" may be based on scientific evidence and/or on the perspectives of consumers, expert practitioners and educators.

The discussion and best practice statements in this project were based primarily on a review of the scientific literature. The report distinguishes between "some", "moderate" and "good" levels of evidence using the following criteria:

Some evidence:

- 2 or more case studies or evaluations without control or comparison groups, or
- 1 quasi-experimental study (i.e., non-random comparison group)

Moderate evidence:

- 2 or more quasi-experimental studies, or
- 1 controlled study (i.e., random control group)

Good evidence:

- 2 or more controlled studies

However, many aspects of FAS/FAE and other substance use have not been empirically tested. The reasons for this include the fact that a fully experimental study design calls for a portion of a sample to receive no intervention, which presents important ethical concerns. In addition, when measuring the impact of an intervention, it is difficult to control for various confounding factors, such as family functioning, which may have significant impact. Consequently, where there was a lack of empirically tested evidence, best practice statements are based on other forms of evidence, including the perspectives of consumers, expert practitioners, educators, the steering committee, and other stakeholders. Where best practice statements relied on the views of stakeholders, rather than on scientific evidence, it is clearly stated.

1.3 Key Definitions

The following key definitions refer to the various points in the development of FAS/FAE (from prior to the development of FAS/FAE, to identifying FAS/FAE and finally dealing with its consequences).

Prevention activities address issues up to the birth of the child and are intended to promote health, prevent alcohol and other drug use during pregnancy, prevent conception while substances are used, or reduce the harm arising from substance use during pregnancy.

> *Primary prevention* activities are undertaken with a healthy population to maintain or enhance physical and/or emotional health. Such activities focus on individual *behaviour* change, systems or environments. Examples of primary prevention activities include raising public awareness, community education and alcohol control measures.
>
> *Secondary prevention* activities aim to address a problem before it becomes severe or persistent. Examples of secondary prevention activities include outreach, screening and referral for women who are pregnant, or of child-bearing age, and using substances.
>
> *Tertiary prevention* activities are for individuals in whom the condition has already developed. Activities include providing substance abuse treatment or birth control services for women who are at-risk of having a child affected by prenatal substance use, or women who have already given birth to a FAS/FAE or other substance use affected child.

Identification activities involve screening, referral and diagnosis of newborns, children, adolescents or adults affected by prenatal substance use. Screening may occur within a variety of settings such as social and health care, legal, educational or vocational. Diagnosis is carried out by medical specialists in conjunction with multidisciplinary teams. Assessment may occur prior to or following diagnosis and in either case, elaborates on the person's abilities and attributes beyond that provided by the diagnosis.

Intervention activities are intended to prevent or reduce the harm associated with primary and secondary disabilities. These activities are directed to individuals with FAS/FAE or other drug effects, including infants, children, adolescents, and adults. Examples of such activities include strategies for improving management of the child, parenting, family support, or special interventions with respect to schools, vocational training, young offender or criminal justice settings.

2. Epidemiology

A range of harmful effects is associated with substance use during pregnancy. Alcohol use can result in FAS or FAE and is a leading cause of preventable birth defects and developmental delays. In population-based studies, FAS is estimated to occur at rates of 1-2 per 1,000 live births, while rates of FAE are less well understood, but estimated to be higher (Abel and Hannigan, 1995). These rates are comparable to the rates for Down syndrome (DS) and spina bifida, two familiar forms of developmental disability. In some Canadian communities, the incidence of FAS far exceeds that of DS or spina bifida (Williams et al., 1999; Robinson et al., 1987).

While FAS is caused by prenatal exposure to alcohol, effects vary widely. Individuals exposed to significant amounts of alcohol *in utero* may manifest all or only some of the symptoms of FAS, called FAE (or more recently termed partial FAS (or pFAS)), while others appear unaffected. The outcomes for a fetus exposed to significant amounts of alcohol are influenced by the pattern of alcohol exposure, i.e., the threshold amounts of alcohol in the blood as well as the timing of exposure during the pregnancy. While not directly causal, other factors, such as maternal health and nutrition, genetic susceptibility, and use of other psychoactive substances may also be factors in the outcome (Stratton et al. [eds.], 1996; Abel and Hannigan, 1995; Streissguth and Dehaene, 1993).

Though FAS is thought to be the result of heavy maternal alcohol use, the threshold of exposure which results in fetal damage has not yet been determined (Passaro and Little, 1997). In a recent review of the literature on moderate drinking and reproductive outcomes, Passaro and Little (1997) found the literature inconsistent, with some studies finding adverse effects including birth weight, gestational age at delivery, miscarriage and stillbirth, congenital anomalies, developmental performance and neuro-behavioural problems, while others found no such problems associated with moderate drinking. They conclude that these inconsistencies may be related to different patterns of alcohol consumption that are masked by averaging. Discrepancies in reproductive outcomes may also be affected by the timing of the exposure, the way in which alcohol use is recalled or measured, and factors such as socioeconomic status.

Exposure to other substances during pregnancy, either alone or in conjunction with alcohol, can also cause problems for the developing fetus[1] that may have long-term consequences. This review was limited to the effects of stimulants (including cocaine), cannabis, opiates, hallucinogens, and inhalants, and did not review the effects of nicotine, caffeine, anticonvulsants or other psychoactive substances on the developing fetus. Of these, benzodiazepines have been shown to cause facial anomalies (Dolovich et al., 1998) while anticonvulsants, such as phenytoin, are known to cause structural birth defects and neuro-developmental effects similar to FAS (Moore, 2000; American Academy of Pediatrics, 1979).

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[1] The American term "fetus", as opposed to the Canadian term "foetus", is used throughout this document to concur with the term FAS. Where individual authors have used the spelling foetus and foetal, this is reflected in the references but not the text.

The issues surrounding the diagnosis of fetal drug exposure have been less well documented. Women with substance use problems often use more than one substance, making it difficult to determine the unique contributions of each substance. Animal studies have helped to document the overwhelming effects of alcohol on the developing fetus, while providing less information on the more subtle effects of other substances (Olson and Burgess, 1997).

Another area of concern is the possible effect of paternal drinking and other substance use on fetal outcome. In a review of this literature, Passaro and Little (1997) concluded that animal studies associating paternal drinking and reproductive outcome were suggestive, though conflicting. Similarly, the few epidemiological studies to investigate this issue have not produced clear findings. The biological mechanisms by which a father's drinking may affect fetal outcomes are not well understood.

2.1 Epidemiology of Alcohol Use and Pregnancy

When planning prevention programs, it is critical to understand the nature and scope of the problem; in this case, the rates and circumstances of alcohol use by women of child-bearing age, pregnant women, and women who have given birth to a child affected by alcohol. However, accurate information concerning alcohol use by women, particularly pregnant women, is often limited due to a lack of routine screening and under-reporting of alcohol use by women in clinical interviews (Finkelstein, 1993).

2.1.1 Alcohol Use by Women of Child-bearing Age and Pregnant Women

According to a number of provincial high school surveys, approximately two-thirds of adolescent females are current drinkers of alcohol (i.e., within the past 12 months) (Anderson, 1998). This figure represents an average of females from Grade 7 to Grade 12 (13 in Ontario); the percentage of drinkers increases with age through these years, with approximately 80% of female students at age 17 drinking alcohol. There are indications that rates of frequent and per-occasion drinking among Canadian high school students have increased significantly during the 1990s (Adlaf, et al., 1999). Less information is available for street or out-of-mainstream youth, but indications are that the percentage of these females drinking alcohol is higher, and that their pattern of use is riskier than their high school counterparts (Anderson, 1993). Both out-of-mainstream females and those in school are much less likely than males to drink at hazardous levels (Adlaf et al., 1999; Anderson, 1993); however, those that do are clearly at-risk of exposing their child to alcohol *in utero* if they become pregnant.

Based on the most recent National Population Health Survey (NPHS), half of adult women 25 to 44 years of age are regular drinkers; 12% drink 7-13 drinks per week; 4% drink 14 or more drinks a week; regular drinkers are more likely to be residents of Quebec and the Western provinces than the Atlantic provinces; the regular heavy drinking pattern is more common among younger women than older women; regular heavy drinking rates doubled among young women 20-24 years of age between 1994/95 and 1996/97 and may pose a particular risk to the developing fetus because of the high blood alcohol levels (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999).

The NPHS and the National Longitudinal Survey of Children and Youth (NLSCY) have examined the prevalence of alcohol use during pregnancy (Dzakpasu et al., 1998). These are both national surveys for which self-reported data are collected every two years. In 1994, the NPHS asked mothers with one or more children under the age of five years about their alcohol consumption during their most recent pregnancy. In 1994/95, the NLSCY asked similar questions of mothers of children under two years of age.

Although each survey used slightly different methods, the results were similar, with 17% to 25% of women reporting drinking alcohol at some point during the pregnancy, and 7% to 9% reporting drinking throughout the pregnancy. Alcohol use during pregnancy increased with age, was more common among women with higher incomes and among married women, and was highest in Quebec and lowest in the Atlantic provinces. However, the relationship between demographics and amount consumed or frequency of consumption during pregnancy was not examined.

Of those who reported consuming alcohol while pregnant, 94% reported consuming less than 2 drinks on the days that they drank, 3% had 3-4 drinks and less than 3% reported drinking 5 or more drinks per occasion. As binge drinking (i.e., drinking 5 or more drinks per occasion) has, along with frequent drinking, been cited as a risk factor for having a child with FAS (Ebrahim et al., 1999; Abel and Hannigan, 1995), this small group of child-bearing women is at significant risk. Studies examining the magnitude of the risk associated with frequent consumption of smaller amounts of alcohol are inconclusive (Passaro and Little, 1997), but the risk is assumed to be lower than that associated with binge drinking (Abel and Hannigan, 1995).

Population-based data from the Yukon indicate that 4% of women are heavy frequent drinkers (Yukon Health and Social Services, 1995). Studies of individual northern communities suggest high rates of alcohol consumption by pregnant women. Godel et al. (1992) reported on alcohol consumption patterns in two communities in the Inuvik region of the Northwest Territories. Of 162 pregnant women surveyed, 34% drank alcohol during their pregnancy. Consumption rates were highest among women of mixed racial origins (48%) and lowest among Inuit women (22%). Binge drinking of 5 or more drinks per occasion was associated with decreased head circumference in the offspring of these women. Decreased head circumference is a marker of decreased brain growth and one indicator of FAS (Stratton et al. [eds.], 1996). Godel et al. (2000), in a later study of a third community in the Northwest Territories, found that 24% of mothers of children in Grades 1 to 3 reported binge or frequent drinking during their pregnancy for those children.

Dow-Clarke et al. (1994) examined health behaviours of pregnant women in Fort McMurray, Alberta, a relatively isolated and affluent northern community developed around an oil-sands project. The researchers noted that 49% of pregnant women reported drinking alcohol after their pregnancy was identified, whereas 70% had reported drinking alcohol prior to pregnancy recognition, and 90% during the last year. Data on drinking patterns such as binge drinking were not collected. Attitudes towards drinking during pregnancy varied; 17% reported reducing or eliminating drinking as a method to improve their health during pregnancy, whereas 43% felt that drinking during pregnancy was "okay".

National and provincial figures are comparable to US data, which indicate that approximately 12% of women (18-44 years) report "risk drinking" (defined as 7 or more drinks per week or 5 or more drinks on any occasion), while 1 out of 29 (3.5%) of women who know they are pregnant report risk drinking (Ebrahim et al, 1999).

Data on Canadian Aboriginal women are sparse and usually included in larger data sets. For example, Williams et al. (1999) collected hospital record data to estimate the incidence of FAS in Northeastern Manitoba among a population of mostly Aboriginal descent. They found that, among the 745 births in Thompson, Manitoba, in 1994, 26% of the mothers drank alcohol during pregnancy, as noted by the clinician or reported by the mother.

Through a series of interviews with Yukon residents, Kellner (1998) confirmed another survey result: that Aboriginal women are more likely than men or non-Native women to abstain from alcohol. However, when they do drink, they are more likely to drink heavily.

In the US, Kvigne et al. (1998) screened 177 US Northern Plains Indian women for substance use problems during pregnancy. Women who drank during pregnancy were compared to women from the same tribal group who did not drink during pregnancy. Women who drank were more likely to be single, less educated, have less access to transportation, smoke, use other substances, and have alcohol dependence in their families of origin. They were also more likely to have experienced physical and sexual abuse. Fifty-six per cent of the women reported drinking during their pregnancy and almost half of them reported binge drinking of 5 or more drinks per occasion. Women who did bringe drink were not analysed separately, so that characteristics differentiating those who drank at the highest risk levels could not be ascertained. This rate of binge drinking is much higher than in the Canadian population-based studies cited above.

Zahnd and Klein (1997) surveyed close to 300 American Indian pregnant or parenting women who were in contact with community agencies in the Western US. Sixty-eight per cent indicated having experienced a personal alcohol-related problem, with 73% and 70% reporting a drinking problem at some point on the part of a parent or spouse/partner, respectively.

As Passaro and Little (1997) have pointed out, many studies assess drinking patterns in terms of the average number of drinks consumed per day either prior to pregnancy recognition or during the pregnancy. The use of a "drinks per day" measure obscures the effects of binge drinking by averaging drinking as if it occurred daily. Many binge drinkers report occasional drinking days, once or twice a month, depending on financial resources; however, this pattern presents a level of risk that may not be apparent from an average number of drinks per day measure.

2.1.2 Characteristics of Women At-risk of Having a Child Affected by Alcohol Use During Pregnancy

Women who are using substances at-risk levels, estimated to be 3% to 4% of women (Hankin and Sokol, 1995), are targets for secondary and possibly tertiary prevention activities. Information on the characteristics of women at-risk is mainly available from clinical populations, and may not necessarily reflect the full range of women whose drinking patterns place them at-risk.

The Motherisk Program in Toronto offers a toll-free number for counseling for women concerned about substance use during pregnancy. Gladstone et al. (1997) compared a sample of pregnant women who had, according to their records, reported binge alcohol consumption with a comparison group that sought counseling for other reasons, between 1985 and 1994. The 272 women reporting binge drinking were more likely to smoke cigarettes, use various illicit substances, and to be young, single and white, than the comparison group. Most of the women reporting binge drinking (83%) had binged fewer than 10 times during their pregnancy. Of these, 84% had a binge early in the first trimester. A considerable proportion of the binge-drinking sample (34%) reported an average of 8 or more drinks consumed per occasion, with students and illicit drug users reporting the highest average amount.

The sample of women who call in to a toll-free number for information may not be representative of all drinking pregnant women. Women who do not have easy access to a telephone, such as women living in isolation, in poverty or who are homeless, would be less likely to use such a service, and thus be under represented in the Motherisk sample.

In a study for the US Center for Disease Control and Prevention, Ebrahim et al. (1999) compared drinking pregnant and non-pregnant women to identify characteristics of pregnant women whose drinking was "risky" (i.e., 5 or more drinks per occasion or at least 7 drinks per week). They used the Behavioral Risk Factor Surveillance System data from 46 states. Pregnant women were one-fifth as likely as non-pregnant women to drink in at-risk patterns over the course of the study. Pregnancy-related reduction in binge drinking was smallest for black women, and largest for women under 30 years of age, and for those who had quit smoking. At-risk drinking by pregnant women was independently associated with being unmarried, being employed and currently smoking. Notably, after controlling for various other factors, risk drinking increased four-fold, from 0.7% to 2.9% between 1991 and 1995 among pregnant women, whereas frequent drinking among non-pregnant women remained stable (approximately 11%) during the same time period.

Testa and Reifman (1996) studied 159 pregnant women who drank prior to pregnancy recognition. They assessed perceived riskiness of drinking, self-report of alcohol use, previous pregnancy outcomes, and lifetime alcohol use. Women in their first pregnancy perceived drinking during pregnancy as more risky than did those who had a previous child. Women who had, in their own opinion, a previous healthy pregnancy outcome, and those with a history of alcohol problems, had lower perceptions of risk. Thus, women who drank during a first pregnancy and had a healthy outcome experienced a decrease in their perception of risk, a factor that can lead to increased drinking during subsequent pregnancies.

Jacobson et al. (1998) have noted that maternal age is a factor influencing the likelihood of having a child affected by alcohol use during pregnancy (although FAS occurs with children of teen and young adult mothers). Infants born to older (30+) women who drank heavily were more likely to be functionally impaired than were infants born to younger women who reported similar patterns of alcohol consumption. The mechanisms underlying this phenomenon are unknown.

Lex (1990) has noted the high incidence of multiple substance use in women in relation to men. Many women report being introduced to substance use by a spouse or common-law partner, a pattern that is not common in men. Lex (1990) further noted high rates of mental illness, family violence, and sexual abuse in substance-dependent women, suggesting that many women self-medicate mental illness and other family problems by using substances. Lex (1990) suggests that many women seek help for these related problems, but are not screened for substance use problems. They may be prescribed psychotropic medications for their mental health problems, which, together with untreated alcohol dependence, increases the potential for dual dependency.

2.1.3 Characteristics of Women Who Have Given Birth to a Child Affected by FAS or Related Effects

Women who have given birth to a child affected by alcohol use during pregnancy are considered high risk for giving birth to subsequent children affected by prenatal alcohol use (Hankin and Sokol, 1995). Studies of women who have given birth to one or more children with FAS come mainly from the United States. American studies of mothers of children with FAS and related effects have shown that women who have low levels of literacy, are of minority status, or are living in poverty, are over-represented (Ernst et al. 1999). Clarren (1999), in a recent presentation, noted that, in his clinic, mothers of children diagnosed with FAS began drinking early in their lives, had histories of severe unresolved abuse, had mental health problems (including agoraphobia), were generally living with partners who did not wish them to enter treatment, were involved in drinking subcultures, feared abandonment by family or friends if they stopped drinking, and about 20% had alcohol-related organic brain dysfunction. Many of these characteristics, which can be found in all socio-economic classes, races and cultures, are also true of women using specialized substance abuse treatment services (Weisner and Schmidt, 1993).

Nanson (1997) noted that, in a Saskatchewan clinic for children with FAS and related effects, many of the biological mothers reported that the pregnancy that resulted in the affected child had been unplanned and unwanted, and sometimes occurred as a result of sexual assault. Further, many women reported experiencing domestic violence for the first time during the pregnancy. Horrigan et al. (2000) found a high correlation between heavy substance use, mental health and exposure to violence among a sample of 271 women registered for prenatal care in an Ohio hospital.

Lex (1990) noted that physical dependence on alcohol has negative effects on female reproductive health, including amenorrhea, anovulation, luteal dysfunction, ovarian atrophy, spontaneous abortion, and early menopause. These findings suggest that the most severely alcohol-dependent women may be less likely to conceive and bring an affected fetus to term, whereas women who binge drink (often younger women), but sober between binges, are more likely to produce an affected child.

2.2 Epidemiology of Other Substance Use and Pregnancy

The extent of other substance use (i.e., stimulants, cannabis, opiates, hallucinogens, and inhalants) by pregnant women and women of childbearing age is challenging to estimate. The illegality of these substances heightens the stigma associated with use and makes it less likely that women who experience problems will come forward for help. Further, screening for these other substances is not routine in most settings and tools for screening are less developed.

Based on results from Canada's Alcohol and Other Drugs Survey, 1994, cannabis is the most widely used illegal drug in Canada, with the highest rate of use among those 15-24 years (prevalence of past year use ranges from 25% at age 15 to 19% at age 24). Among all females 15 and older, only 5% report current (last 12 months) use of cannabis. Other than cannabis, rates of other substance use by Canadian women of child-bearing age are very low. Though the survey report does not provide rates of use for each individual drug, it does report on use of at least one of cannabis, cocaine/crack, LSD, amphetamines and heroin, and indicates that lifetime and current use rates for women are 19.4% and 4.9% respectively (MacNeil and Webster, 1997).

Canadian population based data of other substance use during pregnancy is not available. However, a US general population survey in 1995 found that an estimated 7.2% of all women of child-bearing age used an illegal substance at least once in the past month, whereas 2.3% of pregnant women reported use of these substances in the same period (Howell et al., 1999). In another national US study conducted in hospitals following delivery, 5.5% of women reported use of an illegal substance during pregnancy. Cannabis was the most commonly reported substance used (2.9%), followed by cocaine (1.1%). In contrast, 18.8% reported alcohol use and 20% reported smoking, but patterns of use (i.e. binge drinking) were not collected (U.S. Preventive Services Task Force, 1996).

2.2.1 Characteristics of Women at-risk of Having a Child Affected By Other Substance Use During Pregnancy

Loebstein and Koren (1997) reported on data collected from women counselled by the Motherisk Program in Toronto. They found that the sample of pregnant cocaine users studied can be divided into two groups: dependent users and social users. Dependent women generally used cocaine throughout their pregnancies, along with other substances such as tobacco and alcohol. Dependent women were also more likely to be of lower socio-economic status and less likely to receive adequate prenatal medical care. Social users, on the other hand, generally stopped using cocaine once the pregnancy was discovered, were of mixed socio-economic status, and maintained satisfactory prenatal medical care.

Fried (1996) reported on a longitudinal study of children, born to women in the Ottawa area, who used varying levels of cannabis during pregnancy. Women who used cannabis regularly during their pregnancy (more than 5 joints per week) were of lower socio-economic status, had less formal education, more cigarette usage, and were younger than non-users.

An evaluation of the Breaking the Cycle Program in Toronto, designed for pregnant and parenting substance-abusing women and their young children, collected data on 120 client families. Of these, more than 25% had no permanent residence, the majority of mothers did not have any other adult support available in the home, and 75% were single, separated, divorced or widowed. The average educational level attained was Grade 10; most were unemployed; most had annual incomes of less than $15,000; almost half (43%) reported they had legal problems; the majority reported serious emotional problems; and between 10% and 50% of all mothers attending the program were abusing substances at intake (Leslie et al., 1999).

In a study of women with significant substance use and health issues living in downtown Vancouver, 23% of the mothers had used cocaine, 18% had used hallucinogens, 10% had used injection drugs, 10% had used Talwin and Ritalin, and 8% had used opiates; and 91% had used alcohol (Loock et al., 1993). When compared to women living in the same downtown area of Vancouver who did not use illegal substances or alcohol during pregnancy, the high-risk women were more likely to be single, have less family support, and to be of Aboriginal status.

In the US, prevalence of illegal substance use is generally higher among mothers who smoke, drink, are unmarried, are not working, have public or no insurance, live in urban areas and receive late or no prenatal care (U.S. Preventive Services Task Force, 1996).

Also in the US, Waters et al. (1997) interviewed 30 young women who were heavy current substance users. These women reported high rates of childhood physical and sexual abuse, coercive adolescent sexual relationships, early first sexual contact, early first pregnancies, abortions, and chemical dependency, especially during pregnancy.

2.3 Summary

Patterns of heavy per-occasion drinking (5 or more drinks per occasion) and frequent drinking (7 or more drinks per week) by a woman during pregnancy are both associated with FAS and FAE. Other factors, such as the mother's age, health, use of other substances, and the genetic susceptibility of the child, also affect the likelihood and severity of disabilities in the child.

Rates of frequent and per-occasion drinking are highest among younger Canadian women (age 15-24), with indications that these rates increased substantially during the 1990s. Approximately 20% of Canadian women report drinking during pregnancy. Of these women, less than 3% report drinking 5 or more drinks per occasion.

Information on Canadian women who report risky drinking during pregnancy is sparse; however, there is some indication they are more likely to smoke cigarettes, use various illicit substances, and to be young and single. It appears that rates of heavy drinking by pregnant women may be much higher in northern communities than in the general population.

According to US research, women most likely to have an alcohol-affected child are those who live in difficult socio-economic circumstances, have experienced family violence (including sexual and physical abuse), have mental health problems, and associate with networks that emphasize heavy drinking.

Limited Canadian data indicate that heavy users of other substances are more likely to use throughout the entire pregnancy, and use tobacco and alcohol. There is some indication that they are also more likely to be single, of low socio-economic status, have less family support and serious emotional problems.

Section II: Results

3. Primary Prevention

Primary prevention activities are undertaken with a healthy population to maintain or enhance physical and emotional health. Primary prevention activities typically focus on behaviour change, systems, or the environment.

3.1 Population Health Promotion

At the broadest level, primary prevention takes a population health approach that seeks, through public policy, to address the socioeconomic factors that have been shown to affect the health of a population; for example, education, employment, income levels and social support. Although the picture is far from complete, epidemiological data presented for Canada and the US suggest the prevalence of FAS and FAE is greater in lower socio-economic families and communities. Indeed, the socioeconomic status and circumstances of the biological mother have been described as "permissive factors" in the prevalence of FAS (Abel and Hannigan, 1995).

The Canadian Federal, Provincial and Territorial Advisory Committee on Population Health (1994) has endorsed a framework intended to address these broad determinants of health. This framework has led to activities to address the overall health of "at-risk" pregnant women, through programs such as the Canada Prenatal Nutrition Program (CPNP). These programs have the potential to address substance use issues, mental health and violence issues, as they co-occur (Clarren, 1999; Ernst, et al., 1999; Horrigan et al., 2000).

3.2 Alcohol Control Measures

Various regulatory approaches have been recommended, and in some jurisdictions implemented, to reduce alcohol consumption (for example, increased taxation, advertising regulations, responsible service, and limiting hours of service or number of outlets).

The regulatory measure to reduce consumption that is most supported by evidence is increased pricing through taxation. A number of studies have shown alcohol consumption, even among heavy drinkers, to be quite responsive to price, with one study showing women reducing their consumption due to price increases more than men (Abel, 1998a).

A number of Ontario communities have adopted municipal alcohol policies that reflect a health and safety orientation. An evaluation of a community alcohol policy initiative using comparison communities failed to demonstrate an impact on general population consumption (Giesbrecht and Douglas, 1990); however, those municipalities that fully implemented a municipal alcohol policy reported a decline in alcohol related problems (Douglas et al., 1997).

An alcohol policy initiative on a native reserve in Ontario led to greater regulation of the sale and service of alcohol at events. Early findings indicate a reduction of some problems; however, drinking during pregnancy is not discussed (Lauzon et al., 1998).

In an aggressive attempt to limit consumption, some isolated northern communities have opted to prohibit the sale of alcohol in the community. Early evidence from one study in Alaska suggests that a community alcohol ban resulted in a significant reduction in heavy alcohol use among pregnant women in the short-term (Bowerman, 1997). Aside from this preliminary report, the potential effects of such regulatory approaches on the prevalence of heavy alcohol use during pregnancy have not been studied (May, 1995). However, if prohibitionist policies do not have broad community support, they can result in unintended negative social or community effects, such as increased criminality. These effects need to be considered in evaluating effectiveness (Skirrow and Sawka, 1986).

3.3 Public Awareness Approaches

Another primary prevention strategy is mandated alcohol container warning labels. In the US, legislation requiring the labeling of all alcohol bottles came into effect in November, 1989. Hankin (1994) found an initial increase in FAS awareness, and a decrease in alcohol consumption during pregnancy, following the implementation of this legislation. Unfortunately, this reduction only occurred in women whose drinking patterns placed them at low risk. Women who drink heavily during pregnancy do not appear to be affected by warning labels. Furthermore, the initiative was criticized as the labels lack uniformity, and are harder to see than US cigarette package warnings (Blume, 1996).

Graves (1993) compared the awareness of the adverse consequences of drinking during pregnancy in the US where there is mandatory labeling, to Ontario residents, where there is no mandatory labeling. Small increases in awareness in the US sample were found. Men aged 18 to 29 who were heavy drinkers were most likely to be aware of the warning labels.

In one of several related studies, Greenfield et al. (1999) found that higher proportions of the young, male heavy-drinking population were more aware of the labels. Greenfield et al. (1999) also found a positive relationship between the amount of exposure to the label and conversations about drinking and pregnancy; awareness of the labels was not limited to the most health conscious.

Fenaughty and MacKinnon (1993) studied the effectiveness of a legislated warning poster in the state of Arizona. The poster was required in all establishments selling alcohol, and included the statement, "*Warning: Drinking Distilled Spirits, Beer, Coolers, Wine And Other Alcoholic Beverages During Pregnancy Can Cause Birth Defects*". They sampled college students' knowledge of the effects of drinking during pregnancy prior to and after the implementation of the poster law. Students were primarily young (mean age 20 years) and white (81.4%). The proportion of subjects who had consumed at least one alcoholic drink in the past month was 77%. Following the implementation of the poster law, students were more aware of the poster and its message, but it had minimal impact on their beliefs regarding the effect of alcohol on the fetus. Women and older subjects were more likely to be aware of the poster than men or younger subjects. Data regarding any potential changes to the students' drinking behaviour were not collected.

In Canada, despite interest from various groups, the only jurisdiction requiring alcohol beverage warning labels is the Yukon. The labels were implemented as the result of a policy decision rather than legislation. Some municipalities in British Columbia have by-laws mandating posted information on the effects of alcohol use during pregnancy. The impact of these regulations has not been evaluated.

This review located descriptions of several non-mandated awareness-raising initiatives from a number of jurisdictions in Western Canada (Casiro et al., 1994; Asante and Robinson, 1990; Ridd, 1999; Saskatchewan Institute on Prevention of Handicaps, 1999; Kellner, 1998). These programs have included media campaigns, billboards, warnings on till slips in liquor stores and on alcohol beverage packaging, primarily bags. Unfortunately, the goals of such programs are generally not clearly articulated, making it difficult to judge their effectiveness. For example, it is not clear whether the goals of such programs are to change the behaviour of high-risk women, to prevent any drinking or other substance use during pregnancy, or simply to create public awareness of the issue.

In Manitoba, a television campaign using public service announcements that ran during prime and non-prime time hours for 10 weeks was evaluated (Casiro et al., 1994). Investigators surveyed the same general population sample before and after the mass media campaign on a number of prenatal health questions, and found that the alcohol-related questions were the only ones where awareness had changed.

Given the tremendous array of messages generated by today's media, one of the factors limiting the effectiveness of public awareness campaigns could be that a particular message is simply not seen enough. Kaskutas and Graves (1994) reported on a US national study of those exposed to pregnancy and alcohol messages, and found a positive relationship between the number of exposures to multiple message sources and reduced drinking in the overall population, including women under 40 years of age. However, the design of the study could not establish causality, and the authors acknowledge that behaviour change can bring about heightened awareness of messages.

Statements and guidelines published by credible sources can be important tools for creating awareness of an issue. In 1993, the Canadian Centre on Substance Abuse (CCSA) and the (then) Addiction Research Foundation (ARF) of Ontario jointly published low-risk drinking guidelines (Anderson et al., 1993). These guidelines included the advice to pregnant women that they would be advised to abstain from alcohol, and, given the relatively higher risk involved in the first trimester, that women who are planning a pregnancy avoid drinking. Another key Canadian publication, the *Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) in Canada*, led by the Canadian Pediatric Society and signed by 19 organizations (Health Canada, 1996), was an important effort to provide consensus-based guidance to health care professionals. While both of these publications were widely circulated, neither was evaluated for its impact.

Some FAS awareness raising messages have been criticized as "alarmist", leading to unnecessary anxiety, and possible termination of pregnancy in low-risk women, while failing to reach the women at greater risk (Reynolds et al., 1994; Koren, 1996; Abel, 1996).

Unless research can establish a safe threshold of consumption of alcohol for pregnant women, public awareness campaigns must navigate a fine line. They must avoid creating undue anxiety in women who may have inadvertently exposed their fetus to small amounts of alcohol or other substances on the one hand, while creating awareness of the risks associated with particular patterns (for example, frequent and binge drinking), and particular sub-populations (such as multiparous women who drink during pregnancy), on the other hand. Reynolds et al. (1994), as a result of assessing the need for drug-related health promotion materials for pregnant women in Canada, recommended that materials and messages be developed with very specific groups in mind, avoid fear-arousing messages, and reflect the hierarchy of risk that exists.

In spite of their limited effectiveness, Fenaughty and MacKinnon (1993) suggest that public awareness campaigns may be effective in the long-run in preventing women from developing drinking patterns that would place them at-risk when pregnant. May (1995) also speculates that public awareness efforts may "spark" behaviour change in a way similar to that attributed to public information on smoking and heart disease. Others suggest that women who are attempting to avoid alcohol and other substance use during pregnancy need support from their partners, family and communities, and that public awareness campaigns can help engender this support (Finkelstein, 1993, 1994; Little et al.,1990). Finally, it has been suggested that an informed public may be more inclined to support public expenditures to address this issue (Streissguth, 1997).

3.4 Multi-component Awareness Strategies

Multi-component programs typically aim to increase awareness of FAS among both men and women through a variety of means. Perhaps the most promising use of awareness-raising campaigns is as one part of multi-component community-wide programs. The Tuba City program involving Native populations in the US used a comprehensive approach to prevention and intervention that included awareness raising, training and a diagnostic component (LeMaster and Connell, 1994). Although the various elements of the initiative were not separately evaluated, the overall program was effective in promoting referrals and abstinence among pregnant women.

A well-designed multi-component campaign by the Alberta Alcohol and Drug Abuse Commission (AADAC), on behalf of the Alberta Partnership on FAS, was conducted during 1999-2000. Among other aims, the campaign intended to increase the awareness and profile of FAS. It employed television, radio and newspaper advertisements, and local initiatives that included private sector involvement. Eight hundred Albertans were surveyed prior to the campaign, with another sample surveyed immediately following the three month television campaign. A generally high level of awareness and support for action remained unchanged as a result of the campaign, according to a number of measures. However, public recall of information related to alcohol and pregnancy rose with 61% of Albertans reporting having seen, heard or read something about the issue before the mass media element of the campaign, compared to 73% after.

Other studies indicate that multi-component community prevention strategies can affect awareness and, possibly, levels of alcohol consumption by pregnant women (Streissguth et al., 1983; Smith et al., 1986). Elements include fully available birth control, substance-specific information provided to men and women, prenatal and outreach services, and professional training to identify, intervene, and support those at-risk.

3.5 Other Measures

Many employers, particularly medium and larger organizations, have workplace health promotion programs that, while focussing on larger aims, may contribute to primary prevention of FAS. Most company programs do not deal with substance use per se, but with a range of lifestyle behaviours that affect health. Health behaviours are, however, inter-related, and therefore may indirectly affect substance use.

Integral to the prevention of FAS and the effects of other substances is pregnancy planning. Women need to be aware that being sexually active, a frequent or heavy alcohol user, and not using contraception places them at-risk of an alcohol-exposed pregnancy (Floyd et al., 1999). Awareness about FAS issues is generally not sufficient for women in difficult relationships. Negotiating safe relationships, safe sex, and pregnancy planning, in these cases, is not straightforward.

A key target group for primary prevention is adolescents, because of the prevalence of binge drinking and sexual activity among teens. A recent large US study found that age at onset of alcohol use is a powerful predictor of later alcohol problems. The study found that 40% of those who began drinking alcohol at 14 years of age or younger experienced alcohol dependence at some point in their lives, compared to 10% who began drinking at age 20 or older (Grant and Dawson, 1997). By delaying age at onset, substance use/FAS/FAE prevention initiatives have the potential to minimize later problems.

Life Skills Training (Botvin, et al., 1995), a three-year school-based program designed to teach personal and social skills in combination with specific skills to resist social influence to use substances, has been found effective. A comprehensive school program that targeted an entire community using media efforts, a parent program, a community organization and health policy change (Pentz et al., 1989; Perry et al., 1996) also showed some positive effects.

Multi-component programs, involving media, community leaders, parents and the business and religious communities, show some effectiveness in preventing teenage pregnancy. The School-Community Model demonstrated a reduction of pregnancy and increased use of contraceptives over a six year period and may be an example of how to address the issue of FAS/FAE in schools (Paine-Andrews et al., 1996).

FAS-specific content should be accommodated in health education and family living courses. Topics at the high school level should include pregnancy planning, the teratogenic effects of alcohol, early symptoms of pregnancy, the importance of routine physical exams for sexually active female adolescents, the problems of confronting parents, and understanding the needs of those affected by prenatal alcohol exposure (Murphy-Brennan and Oei, 1999).

One such US school program developed for Aboriginal 6th and 8th grade students used a video in conjunction with 19 lessons and a project World Wide Web site. The study used a small randomized sample. It found a significant increase in knowledge after just two weeks (Mai et al., 1998).

3.6 Summary

Measures to control the sale and service of alcohol have shown some effectiveness in reducing heavy alcohol use during pregnancy, at least in the short-term. These measures are more likely to be effective when they have broad community support. The regulatory approach to raising awareness and changing behaviours related to FAS issues through warning labels and posters has only shown some effectiveness among lower risk women. More localized efforts to raise awareness through the use of media have shown little effect used in isolation. Greater impact is seen when they are part of a multi-component initiative. Well-conceived multi-component programs can be effective if they engage members of the community. Several school-based substance use problem prevention programs have demonstrated some effectiveness.

3.7 Best Practice Statements

There is some evidence that measures to limit the availability of alcohol, such as bans on sales and importation that are broadly supported by the community, or price increases, can reduce heavy alcohol use by pregnant women at least in the short-term.

There is some evidence to support warning labels and posters as a means of increasing awareness and effecting short-term behaviour change among low-risk women. However, women who drink heavily during pregnancy do not appear to be affected by warning labels.

There is some evidence to support multi-component community-wide initiatives as a means of increasing awareness generally, reducing consumption for pregnant women, and promoting referrals.

There is moderate evidence to support the use of life-skills-based and multi-component school-community substance use prevention programs as a means of preventing or delaying substance use among youth and, in turn, reducing substance use problems among adults.

4. Secondary Prevention

4.1 Introduction

The aim of secondary prevention is to identify and address a problem before it becomes severe or persistent. When applied to the issue of substance use during pregnancy, secondary prevention activities target women of child-bearing age who use substances, and include outreach, screening, referral and brief intervention activities. The intent is to promote the health of the mother and prevent or minimize harm to the fetus.

Secondary prevention activities can only occur when a pregnancy is recognized, which is often 4-6 weeks or more into a pregnancy. During this period when a pregnancy may not be recognized, damage may occur to the fetus as it is a critical period for alcohol exposure (Floyd et al., 1999). However, the logic of early intervention is compelling. While structural damage resulting from earlier consumption cannot be undone, abstinence or reduction of consumption of alcohol, as late as in the third trimester, has been shown to increase the viability of the fetus (Jones and Chambers, 1998).

Many people with dependencies are able to change their behaviour without professional help (DiClemente et al., 1992). Upon learning they are pregnant, or when planning a pregnancy, women will often quit or cut down on their drinking (Kaskutas and Graves, 1994; Smith et al., 1987). Women less likely to stop on their own include those with a longer history of alcohol problems, with a FAS/FAE child, family members or partners who have alcohol problems, lower incomes, smokers, unmarried women, and those whose social networks emphasize drinking. These women benefit from early identification and supportive interventions (Floyd et al., 1999; Hankin and Sokol, 1995; Testa and Reifman, 1996; Testa and Leonard, 1995; Abel, 1995; Ihlen et al., 1990; Smith and Coles, 1991).

4.2 Barriers to Identification and Intervention

When women with drinking problems seek help they are less likely than men to use substance abuse services, and more likely to use health and mental health services (Weisner et al., 1995). There is some indication that Canadian Aboriginal women may differ in this respect (C. Tait, pers. com., 2000)). This is due, in part, to the added stigma experienced by women with substance use problems, which increases when a woman is pregnant. When asked about reasons for not using substance abuse treatment services, women participating in qualitative research in British Columbia cited "not knowing what treatment was available" and "not knowing what treatment would be like", as further barriers (Poole and Isaac, 1999).

When women seek help from health or mental health services, their substance use problems may go unrecognized because the professionals may lack specific knowledge about FAS/FAE. Lack of routine professional training on substance abuse screening, and advice for FAS prevention, continue to be barriers to obtaining treatment. A lack of designated staff, insufficient staff, insufficient referral protocols, weak referral linkages (staff are reluctant to identify unless they can provide help), poor coordination of services, and lack of transport and child care continue to be further barriers (Howell et al., 1999).

Women less likely to stop substance use on their own may also be reluctant to seek help during pregnancy, due to concerns that their child or children may be taken into legal custody. Legal efforts to punish pregnant women for exposing their fetuses to substances may have the effect of pushing pregnant women with substance use and other serious health issues further from the health care system (Deville and Kopelman, 1998).

A recent qualitative study (Kowalsky and Verhoef, 1999) demonstrated the difficulties inherent in living in an isolated Aboriginal community. They describe the barriers in an unnamed Aboriginal community in northern Canada, which include fear of stigmatization, lack of awareness of the issues, and specific community social problems. They note that substance use problems are embedded in the fabric of other social problems and must be addressed within this context.

Similar problems were reported by those working in a Navajo community in New Mexico (Jordan, 1998), prompting the author to provide guidelines to overcome these barriers, including the use of family advocates, native languages, and resource material published in the local native language.

4.3 Outreach Activities

Outreach activities that address barriers are needed to identify and intervene with those less able to quit drinking on their own. Some outreach effect may be gained from what May (1995) refers to as "trickle down" messages from primary prevention programs. Although it has not been proved, trickle down messages may promote harm reducing action on the part of some women.

Agencies and groups, traditional and non-traditional (e.g., transition houses, community centres, workplaces, churches, schools, correctional settings), that are in contact with women of child-bearing age, are in a position to present harm reduction messages in the context of overall concern for the health of the mother and child. Posters and pamphlets that encourage conversation and questions about substance use and carefully worded remarks that are presented in a supportive, non-critical way (Rosett and Weiner, 1981), can encourage women using substances to postpone pregnancy or, if pregnant, quit their substance use on their own or seek further information or help.

Most frequent and heavy substance users will not alter their use as a result of these messages alone. Therefore, basic messages need to be complemented with a screening function that involves routine conversation concerning substance use. Simple, well worded single questions, incorporated into broader health or nutrition-related questions or demographic information, is one recommended approach to screening in an outreach setting (May, 1995). Kinzie et al. (1993) used a computer-based educational program with a sample of low-income, rural women, and suggested that the program may be a non-threatening way to lead into administration of a screening tool.

Drop-in centres and transition houses or shelters are in a strong position to raise substance use issues with women in a sensitive, respectful manner. Other settings, such as workplace Employee Assistance Programs (EAPs) have been suggested; however, their potential for identifying pregnant women with alcohol problems may be limited, because many women do not work outside the home, or work in occupations poorly served by EAPs (Russell et al., 1997; Lightfoot et al., 1996).

In targetting women who are hard to reach, on-call outreach workers trained in substance abuse counselling could extend outreach to the streets, thereby increasing access to care for this high-risk population (Howell et al., 1999). Namyniuk et al. (1997) suggests outreach work should involve collaboration with referral sites, education of community agencies and advertisement of programs.

One population warranting a concerted outreach approach is pregnant adolescents (Cornelius et al., 1997). Although there is little current empirical evidence that adolescents are having children with FAS or related effects, there is some anecdotal community-based reporting suggesting occurrence (J. Lutke, pers. com., 2000). Their tendency to recognize pregnancy later than adults and to drink large amounts per occasion may place some adolescents at-risk. Also, prevention of heavy drinking among adolescents may prevent harmful drinking patterns from evolving as they age and the risk for having an FAS/FAE child increases.

McKnight (1990) described an outreach program for pregnant teens that resulted in an increase in use of county services. The program included screening by counselling staff, encouragement by public health nurses, aggressive case management by counsellors and referral to either education, a support group or treatment. The author suggests that education for these young women focus on early symptoms of pregnancy, the importance of routine physical exams, and encouragement to seek prenatal care as early as possible.

4.4 Identifying Women with Substance Use Problems

A principal aim of outreach activities is to refer women to prenatal education and counselling, where attention to substance use is routine and institutionalized (May, 1995). Time pressures may make routine screening difficult to implement; however, it is critical that decisions to screen not be left to individual discretion (U.S. Preventive Services Task Force, 1996).

Some women may not acknowledge substance use problems due to a lack of motivation, or fear of discrimination by health care providers. Adolescents may be concerned about substance use being brought to the attention of police or family members (U.S. Preventive Services Task Force, 1996). Consequently, screening needs to occur in a supportive milieu that is sensitive to the circumstances of pregnant women, particularly substance users, and that will permit open questions and honest responses (Russell et al., 1996; Lieberman, 1998a). Anderson et al. (1997) have recommended non-judgmental, non-punitive prenatal care and vigilant screening for substance use problems as important clinical interventions for pregnant women.

Horrigan et al. (2000) studied substance abuse, mental health and experiences of violence among a sample of 271 women registered for prenatal care in an Ohio hospital. Based on the high correlation between these three issues, the authors recommend that evidence of any one of these problems warrants investigation for the other two.

Brief screening instruments are simple and easy-to-use tools for determining whether a person may have an alcohol or other substance use problem. They are primarily used in health care settings, but others in health and social services can administer them, or help the women complete the questions. The TWEAK has been validated in several different populations, including emergency ward patients of diverse backgrounds (Russell et al., 1996). Russell et al. (1996) evaluated the effectiveness of T-ACE, another screening tool intended for pregnant women, and TWEAK. They found both to be highly sensitive in the detection of risk drinking related to pregnancy. Gale et al. (1998) tested the T-ACE with pregnant Native US women and, although recommending adjustments, found it sensitive for this population.

Midanik et al. (1998) tested pregnant women and revised the CAGE by asking about "past 12 month use" rather than "lifetime use". This was found to be more effective in identifying adult women than adolescents.

Cherpitel (1997) reviewed several brief screening instruments and found The Alcohol Use Disorders Identification Test (AUDIT) and the TWEAK to be more sensitive for women than the CAGE or the brief Michigan Alcohol Screening Test (bMAST). All of the screens were found to be more sensitive for males than females; lowering the cut-off values on the TWEAK, CAGE and AUDIT improved sensitivity without substantially lowering specificity for women.

An advantage of questionnaire screens is that they can be used quickly and in a variety of settings, to identify those who require further assessment (Russell et al., 1996). There is some evidence to suggest that women may report their alcohol use more accurately with self-administered or computer-administered questionnaires than in face-to-face interviews (Russell et al., 1996).

A limitation of screens is the tendency of respondents to under-report their use of alcohol. To minimize under reporting, the T-ACE and TWEAK do not ask women about actual quantities of alcohol used or about current use. Another limitation is that increasing the specificity of screens (that is, the effectiveness in correctly screening out women who do not have alcohol problems) usually means identifying fewer mothers who drink less heavily, but whose drinking nevertheless puts them at-risk for delivering a FAS/FAE infant. It has been suggested that clinicians err on the side of increasing the sensitivity of the instrument (even if non-problem drinkers are identified as well) in order to ensure all problem drinkers are identified, recognizing that more women will need to be given follow-up assessments to verify the screen results, and this will require more resources (Russell et al., 1996; Cherpitel, 1997; Russell et al., 1997).

As the TWEAK and T-ACE do not ask for quantities, Hankin and Sokol (1995) suggest following up these screens with women whose responses suggest alcohol problems and, with sensitivity, ask about current and at-conception amounts of alcohol used.

Bio-markers have been tested as a screening tool. Several studies have found that two tests, Carbohydrate-deficient Transferrin (CDT) and Gamma glutamyl transpeptidase (GGT), when applied together, show increased sensitivity compared to one alone, without reducing specificity (Allen et al., 2000; Stratton et al. [eds.], 1996). Stoler et al. (1998) studied the effectiveness of four bio-markers, including the CDT and GGT, and found the panel of four markers was more effective in predicting an affected child than any one marker on its own, or the women's self-reporting.

Ethical concerns arise with any test that can be applied without the woman's knowledge. It is critical that bio-marker testing be conducted only with a woman's informed consent. Further research is needed before the routine use of laboratory tests can be recommended to identify alcohol risk among pregnant women (Allen et al., 2000; Stratton et al. [eds.], 1996; Stoler et al., 1998).

Brief screening for drug use is not as developed as brief screening for alcohol use. Toxicologic tests are effective in providing evidence of current or recent drug use; however, they have several limitations. Sensitivity for detecting use depends directly on timing of use. For instance, cannabis may be detected for up to 14 days following regular use, while evidence of cocaine, opiates, amphetamines and barbiturates is present for only 2 to 4 days after use. The fact that these tests cannot distinguish between occasional or heavy use is a serious limitation. As well, routine drug testing of pregnant women in a clinical setting who present no indication of substance abuse pose major ethical and legal concerns. It is important that the value of identifying affected children be balanced against the privacy rights of the mother (U.S. Preventive Services Task Force, 1996).

Koren and Klein (1997) found that taking a mother's history and conducting urinalysis was not nearly as effective in identifying cases of prenatal exposure to cocaine as hair analysis of the newborn. Koren et al. (1998) point out that a positive hair sample indicates cocaine use during the last four months of pregnancy. Again, decisions to use this form of testing need to consider the significant ethical implications.

4.5 Brief Interventions

When screening is administered by a health care professional, the indication of a problem may be effectively addressed with brief advice from the physician or nurse. Elements of a recommended brief physician intervention include informing patients of safe drinking guidelines, reviewing relevant health effects, counselling patients to set a goal for abstinence or reduction of consumption, providing tips on reducing consumption asking patients to keep a record, and monitoring the patient's gamma glutamyl transferease (GGT) levels. However, a review of brief physician intervention studies found them to be less effective for women than for men (Kahan et al., 1995).

Alternatively, where a problem is indicated, women may be invited to participate in a specialized program to help them quit or cut down on alcohol use. Sanchez-Craig et al. (1991), in a well designed study, compared two forms of brief self-help therapy to a therapist-led treatment for men and women. The two experimental groups were given variations of a three-session program of instruction for a self-help method based on cognitive-behavioural principles. The women (whether they were pregnant is not known) were more likely to reduce their intake as a result of the brief therapies than the men.

In 1993, Schorling reviewed a number of early interventions for pregnant women. They typically involved home visits or a small number of counselling sessions with a mid-wife or social worker, and/or the provision of written, video and verbal reinforcement. Although some interventions reported high rates of abstinence or reduction, very few of the studies were methodologically sound (for example, only two used control groups), so only tentative conclusions could be drawn. Schorling did not identify any interventions that, in his estimation, were significantly superior to the provision of information alone.

Reynolds et al. (1995) evaluated the effectiveness of Sanchez-Craig et. al.'s (1991) brief self-help approach with pregnant women, using a controlled study design. The researchers tested a 10-minute educational session and a nine-step self-help manual with women attending public health clinics. The quit rate for intervention participants was higher than for the controls receiving standard clinic care (88% vs 69%), but was greater for lighter drinkers than for heavy drinkers.

Another brief intervention demonstrating efficacy with various populations is Motivational Interviewing (Miller et al., 1995). Handmaker et al. (1999a) tested Motivational Interviewing with a small sample of drinking pregnant women in a prenatal care setting. After an assessment, those in the experimental group participated in a one-hour intervention, consisting of discussion of what the woman already knew about the effects of drinking, feedback on the severity of her drinking, and comments intended to increase the motivation to change. Those in the control group were given the assessment and were mailed information on the potential risks associated with drinking during pregnancy. In contrast to Reynolds et al. (1995), the heavier drinking women showed significantly greater reduction of drinking than women in the control group after two months, as measured by peak intoxication.

Chang et al. (1999) conducted a controlled study of the effectiveness of a 45-minute intervention with pregnant women. The control subjects received an initial two-hour assessment of alcohol use and other problems. The experimental group received the assessment followed by a brief intervention, which consisted of:

- Reviewing the woman's general health and course of pregnancy to date;
- Reviewing the woman's lifestyle changes made since pregnancy;

- Requesting the woman articulate her drinking goals and reasons while pregnant;
- Requesting the woman identify circumstances when she might be tempted to drink; and
- Summarizing the session by emphasizing four key points - drinking goal, motivation, risk situations and alternatives - and noting them in a take-home manual.

There was an overall decline in consumption for both the experimental and control participants during pregnancy following the assessment. However, the control group showed a greater decrease, prompting the investigators to speculate that the intervention may have been too short, or that comprehensive assessments may have therapeutic value in themselves.

In a review of brief interventions, Yahne and Miller (1999) summarized the elements of successful interventions, identified by the acronym FRAMES:

- **Feedback:** effective, but brief interventions provide clients with personal feedback regarding their individual status.
- **Responsibility:** effective brief interventions emphasize personal responsibility for change and the individual's freedom of choice.
- **Advice:** effective brief counselling that includes a clear recommendation on the need for change, in a supportive rather than authoritarian manner.
- **Menu:** a menu of different strategies for change is offered, providing options from which clients may choose what seems sensible to them.
- **Empathy:** emphasis is placed on an empathetic, reflective, warm and supportive practitioner style.
- **Self-efficacy:** effective brief interventions reinforce self-efficacy, ie. the client's expectation that she can change.

Heavy drinkers who received screening together with a single session based on FRAMES reduced drinking, in comparison to a wait-list control group receiving no intervention. Similar results were obtained for heavy drinking college students and for heroin addicts, suggesting that this model can apply to other substance use problems (Yahne and Miller, 1999).

Another approach is to address the risk factors associated with women's heavy drinking. One such intervention, focusing on psychosocial stressors, was evaluated with Native and Hispanic women in the US. The rationale was that substance use would be reduced and birth outcomes improved by teaching stress management skills and presenting alternatives to smoking, drinking and other substance use, in a culturally appropriate way. The intervention included training for the health educators who were recognized leaders in the community, use of incentives (make-overs, cosmetic demonstrations, hair styling lessons) to attract clients, and instructions on problem-solving and other stress-reducing strategies. Participation in the intervention group was associated with improved obstetrical outcomes, and reduction of heavy drinking and smoking, suggesting that a low-cost prenatal preparation program, that gives attention to stress and substance use, may be an effective intervention for some pregnant women (Mehl, 1993).

Sarvela and Ford (1993) used a quasi-experimental design to test the effectiveness of a drug education program for pregnant adolescents attending prenatal clinics. The program consisted of eight modules addressing nutrition and the effects of drug abuse and was completed by patients as they waited to see a physician. At post-test, more patients in the experimental group indicated they had quit or reduced drug use compared to patients who received standard prenatal care.

In higher risk communities, outreach, identification, referral and appropriate support need to be woven into overall prevention and early intervention strategies. The previously mentioned Tuba City program, involving Native populations in the US, found that a comprehensive approach to outreach and intervention resulted in a high acceptance of referrals by pregnant women, and 56% of an alcohol-using sample of women abstaining at 18 months (Masis and May, 1991; LeMaster and Connell, 1994). The high rate of client acceptance of referrals was attributed to the initiative being presented as a prevention program rather than a social work or alcoholism program, and the fact that it was hospital-based with trusted professionals (Masis and May, 1991). However, there was no control group used in this design.

Studies have not found a biological effect on fetal development associated with paternal drinking to date; consequently the male's role in the development of birth defects appears to be primarily through social and psychological influence (May, 1998). However, this influence appears to be quite strong, with various studies showing that alcohol use by a partner is associated with use by the pregnant woman (May, 1998). It is reasonable, then, to direct attention to heavy-drinking fathers to influence the mother`s drinking (Ihlen et al., 1990).

Brief interventions have been shown to be effective for some women with substance use problems; however, others will require more intensive treatment and it is important that this be determined as early as possible. Abrams et al. (1996) recommend the use of brief interventions as the first step in a Stepped Care model of service delivery. In this model, clients are assessed according to level of motivation, self-efficacy, level of dependence, co-morbidity and socio-cultural factors, and triaged into one of three treatment levels. A guiding principle of this model is the use of the least intensive level first and "stepping up" a client when a less intensive treatment has not been effective.

4.6 Professional Development Issues

Physicians and other health care professionals, such as nurses and midwives, are in the strongest position to screen women, and to identify those with substance use and other serious health issues (Gardner, 1997). Many authors have identified physicians and nurses, particularly Aboriginal nurses, as critical gatekeepers in this process (Gardner, 1997; Hess and Kenner, 1998; Van Bibber, 1997). A study of physician knowledge by Nanson et al. (1995) concluded that continuing medical education is required to help primary care physicians address the issue of substance abuse and pregnancy.

Handmaker et al. (1999b) used a controlled study design, with a small sample of obstetric care physicians, to test the effectiveness of a 20-minute training videotape on motivational interviewing. Those in the experimental group showed greater empathy, and were more effective in minimizing patient defensiveness and in supporting women's beliefs in their ability to change.

In the state of Washington, the Pregnancy and Health Program (1979-81) studied the effect of educating professionals, and found that distribution of written information, presentations during grand rounds, and continuing education workshops led more obstetricians to ask patients about current alcohol use, recommend alcohol use be limited, and mention FAS as a specific risk (U.S. Department of Health and Human Services, 1987).

Other practitioners, including social workers and human service workers, have opportunities to identify women at-risk. In their qualitative research concerning barriers to treatment facing women in British Columbia, Poole and Isaac (1999) found that supportive professionals from a wide range of services, including justice, health and housing, helped women access treatment. Carr (1995) described a workshop designed to train peer educators to intervene with pregnant women at-risk. Carr (1995) emphasized a need to intervene at the level of the interpersonal needs of the client (e.g., self-esteem issues, or family violence) rather than just providing facts on the risks of drinking during pregnancy.

4.7 Summary

Women who use substances at risk levels may face various barriers when seeking help. Given the problems associated with prenatal alcohol use, routine conversations about substance use, or the administration of brief screening questionnaires, is important in determining women's use of alcohol during pregnancy. Women are more likely to consider taking appropriate action when they feel comfortable. Use of brief intervention programs for early intervention have demonstrated reasonable efficacy.

In contrast, the value of routine administration of brief-screening instruments or toxicology tests to identify early problems with substances other than alcohol is not as clear. There is a lack of evidence supporting their use with pregnant women. As well, there are limitations and ethical concerns pertaining to toxicology technology. Also, evidence supporting the effectiveness of earlier interventions for non-dependent other-substance users (who may be less motivated to change) is weak.

4.8 Best Practice Statements

> *There is a consensus among experts to support routine screening of pregnant women for use of alcohol and other substances in various settings, including justice, housing and health settings.*
>
> *There is moderate evidence to support the use of the T-ACE and TWEAK, and some evidence to support the use of CAGE and AUDIT alcohol dependence instruments in a supportive milieu to identify women who would benefit from intervention for their alcohol use during pregnancy.*

There is some evidence and a consensus among experts to support selective use of bio-markers by physicians, with the informed consent of the client, as a follow-up to a written screen.

There is good evidence that brief interventions in prenatal settings, based on cognitive-behavioural principles, are effective low-cost means of helping pregnant women with early-stage alcohol problems to reduce or eliminate alcohol use during pregnancy.

There is some evidence to support the effectiveness of drug education programs in reducing substance use among pregnant adolescents attending prenatal clinics.

There is some evidence and a consensus among experts that training can be effective in helping physicians and other professionals work with women who have substance use problems.

5. Tertiary Prevention

5.1 Introduction

Tertiary prevention activities target those for whom FAS is already a concern. The aim of tertiary prevention is to minimize the damage to the fetus, reduce the likelihood of further affected pregnancies, and increase the capacity of the mother to care for her FAS children effectively (Astley et al., 2000b). Tertiary prevention involves intensive multi-component activities,including such strategies as substance abuse treatment, birth control, and parenting programs.

Those considered at high risk are women who drink heavily, and/or have mental health problems and/or histories of physical or sexual abuse and are of childbearing age. Also at high risk are women who have already given birth to an FAS child. Studies show that women who have given birth to one FAS child and who continue to drink, are at risk of having subsequent children that are progressively more severely affected (Jacobson et al., 1998; Astley et al., 2000a; Abel and Hannigan, 1995).

5.2 Barriers to Accessing Care

Compared with men, women with substance use and other serious health issues are less likely to access substance abuse treatment services, in part because they are more likely to describe their problems as being related to depression or anxiety and less likely to describe their problems as explicitly related to alcohol (Fillmore, 1984; Beckman and Amaro, 1986; Blume, 1982). Consequently, women are more likely than men to seek help from a physician or mental health service than from specialized substance abuse treatment services (Lex, 1990; Weisner and Schmidt, 1993; Weisner et al., 1995).

Pregnant women with substance use problems may be even less likely to access substance abuse treatment services; the difficulty in doing so is well documented (Howell and Chasnoff, 1999; Howell et al., 1999; Messer et al., 1996; Ernst et al., 1999). In the US, it has been estimated that only about 5% to 10% of pregnant women with substance use problems receive professional treatment (Messer et al., 1996). Many of the reasons presented by pregnant women for not accessing treatment arise from fear of loss of custody of their child, lack of child care, lack of access or priority for pregnant women, and lack of special services and other widely acknowledged systemic barriers (Blume, 1997). Virtually all of a sample of 80 women with substance use issues studied by Astley et al. (2000b) acknowledged a drinking problem. They offered a number of reasons for not wanting to reduce their use: because it helped them to cope (94%); because they were in an abusive relationship (72%); and because they were too depressed to do anything about it (79%).

Their most common reasons for not seeking substance abuse treatment were that: they did not want to give up alcohol (87%), they were afraid they would lose their children (42%), there was no one to take care of the children (40%), and their partner did not want them to go to treatment (39%).

For these and other reasons, a woman may be reluctant to seek help for substance use problems. Some women, on the other hand, may be motivated to enter and succeed at treatment to regain custody of their children who have been placed in foster care because of substance use (Howell et al., 1999). How this form of motivation affects the treatment experience of these women is not clear.

Reasons suggested for the low rate of treatment for pregnant women include the failure of clinicians to identify substance problems among their prenatal patients, and the lack of appropriate treatment and support services for this population (Messer et al., 1996). It has also been found that women who drink during a first pregnancy and have what they think to be a healthy outcome, report a decreased perception of risk (Testa and Reifman, 1996). This may contribute to a disinterest in treatment and to continued or increased drinking during subsequent pregnancies.

Murphy and Rosenbaum (1999) studied the perceptions of 120 particularly marginalized pregnant women with substance use and other serious health issues. All of the women reported that they were concerned about their fetus once they learned they were pregnant, but that the sense of the inevitability of harm to the baby (often arising from media reports) served as an obstacle to doing something about it. Yet most of these women did, in fact, try to reduce the harm to their fetus, such as switching to marijuana, not using on certain days or weeks, eating more, using prenatal vitamins, and sleeping more.

Few of the pregnant women with substance use problems studied by Klein and Zahnd (1997) in California desired or sought substance abuse treatment programs. Other needs such as housing, education, job training, and employment were ranked as greater needs than was substance abuse treatment. Most of these women reduced their substance use substantially on their own as the pregnancy progressed.

Zahnd and Klein (1997) reported on another survey of close to 300 urban and rural American Indian pregnant or parenting women in contact with community agencies. While close to 70% reported alcohol use problems, almost none were interested in treatment, indicating they "could cut down or quit on their own" and "could handle the alcohol and drugs". These women gave much greater priority to economic concerns, such as education and vocational training, job placement, housing and transportation assistance, food and income support and help with health care.

Noting that some women will choose not to enter treatment when it is offered, Messer et al. (1996) compared two groups of women, one of which accepted substance-related treatment services, the other declining the same services. Those who accepted treatment had more severe substance abuse problems, and were more likely to have undergone treatment in the past. These women were also more likely to have partners who used alcohol and were three times as likely to have experienced physical and/or sexual abuse during pregnancy.

Pregnant women dependent on illicit opioids are often marginalized and have a history of difficult relationships with health and social agencies (Ward et al., 1998). As a result, they are at-risk for a range of health and social problems related to the use of illicit drugs and injection drug use. The cycle of intoxication and withdrawal from opioids may stress the fetus and withdrawal during pregnancy can result in fetal death (Ward et al., 1998).

As well, the impurity of many drugs bought on the street and the possibility that such contaminants may be teratogenic, poor maternal nutrition, poverty, violence, homelessness, and use of other drugs may further put the health of the mother and fetus at-risk (Ward et al., 1998; Mitchell et al., 1995).

5.3 Need For Prenatal Medical and Social Attention

Engaging pregnant women who use substances is an ongoing process, but should begin as early as possible in their pregnancy. Engagement is most likely to occur within a supportive, culturally sensitive and non-judgmental environment and needs to lead to a full health and psychosocial assessment (Mitchell et al., 1995). For women whose substance use and personal circumstances (as determined by reproductive and substance use histories) place them at relatively less risk, a brief intervention may be sufficient to support change in use. Women whose circumstances place them at higher risk should receive a substance abuse assessment followed by referral to treatment and, if necessary, detoxification (although the availability of these services for pregnant women is limited in this country). When women visit a prenatal provider, they are unlikely to view substance use as an issue they are ready to work on. Consequently, the process of engagement, assessing the need for treatment and making a successful referral, requires sensitivity and patience (Corse et al., 1995).

The importance of providing both prenatal care and substance abuse counselling for the health of the mother and the baby is highlighted in a US study of cocaine-dependent women by Burkett et al. (1998) which found better outcomes for mother and child with the provision of both prenatal care and drug treatment when compared with prenatal care alone, or neither of these interventions. Though the study results are confounded by the fact that the groups were formed through self-selection, the study does highlight the importance of actively engaging pregnant substance using women in both prenatal care and treatment for cocaine dependence (Burkett et al., 1998).

Anisfeld et al. (1992) compared pregnant cocaine-using women attending a prenatal clinic who were provided with standard care with an intervention group provided with a more intensive and comprehensive range of services, including involvement with the same social worker, drug treatment referral, parenting group, close liaison with medical staff, home visiting and social support/counselling, whenever needed from the initial contact to two years after the birth of the child. Assignment to groups was based on time of enrolment at the clinic. In comparison with the standard care group, the intervention group reduced cocaine use, decreased length of stay for the newborn infant and increased compliance with post-birth nutritional and medical care. The authors of this study point out, however, that women who become drug-free before birth and whose infants are drug-free may still need support services to help them in longer-term recovery and parenting.

All women receiving substance abuse treatment also need to receive counselling on the full range of reproductive options. As women become sober they need to be warned that sobriety may result in a resumption of ovulation and an increased risk of unplanned pregnancy among some. The Centers for Disease Control and Prevention have initiated Project CHOICES to identify and help women at high risk for an alcohol-exposed pregnancy before they become pregnant. Recognizing a need for women who use substances to receive support to institute effective methods of contraception, program goals are to encourage these women to reduce their alcohol intake and to postpone pregnancy until they stop or limit their drinking. The results of this pilot project have not yet been reported (U.S. Department of Health and Human Services, 1999).

5.4 Management of Withdrawal

A *Treatment Improvement Protocol (TIP)* for pregnant substance-using women prepared by a consensus panel sponsored by the U.S. Center for Substance Abuse Treatment includes guidelines for detoxification (Mitchell et al., 1995). According to these guidelines, detoxification for a pregnant, alcohol-dependent woman must be undertaken in an inpatient setting under medical supervision that includes collaboration with an antenatal care provider. The 1995 *Treatment Improvement Protocol* notes that for pregnant women "there are no well documented studies on the safety or efficacy of using drugs to medically withdraw pregnant, cocaine-using women". However, the TIP does provide guidelines for the use of a variety of medications to assist in cocaine withdrawal for pregnant women, including anxiolytics, antidepressants and barbiturates.

The 1995 *Treatment Improvement Protocol* states that, although methadone maintenance therapy (MMT) is the treatment of choice for pregnant women dependent on opioids such as heroin, there are no specific guidelines established for methadone dosage levels for pregnant women. Rather, the trend is towards individualized dosages that are adequate to prevent withdrawal symptoms. Acknowledging the need for clinical judgment concerning dosage, the publication, *Guidelines for Perinatal Care of Substance Using Women and their Infants* (Children's and Women's Health Centre of British Columbia, 1999) provides detailed protocols for physicians concerning dosage and related issues. It is likely that methadone maintenance therapy during pregnancy will result in abstinence or withdrawal syndrome in the newborn, the severity of which depends on a number of factors, including the mother's dosage levels. Nevertheless, a comprehensive approach to MMT that allows for ongoing access to a range of supportive health and social services for the mother, along with medical management of withdrawal for the newborn, is generally considered preferable to terminating treatment and risking relapse to heroin use and a less healthy lifestyle (T. Oberlander, pers. com., 2000). Ward et al., (1998) and the 1995 TIP also discuss the issue of withdrawal from opioids, rather than maintaining a woman on methadone. Though this is not the treatment of choice, both Ward and the TIP provide guidelines for withdrawal, should this be necessary. The TIP also cautions about the dangers of prescribing any narcotic antagonist to a pregnant woman because it could result in spontaneous abortion, premature labour and/or stillbirth.

In relation to dosage levels, the literature on MMT for pregnant women has also addressed the issue of reduced methadone plasma levels and unexpected withdrawal symptoms among women in late pregnancy, leading to risk of relapse. For example, Jarvis and Schnoll (1994) note the need for higher doses to address the increased rate of methadone metabolism in the later stages of pregnancy, as well as the utilization of split daily doses. Jones et al. (1999) and Ward et al. (1998) also note that careful monitoring and adjustment of methadone dose and regimen is required throughout pregnancy, with the possible requirement for increased or split doses.

De Petrillo and Rice (1995) examined daily versus twice-daily methadone doses using a non-randomized control design. They found women on a split dose regime had better urine toxicology compliance rates and a lower percentage of urine screens positive for cocaine, but not opiate use in the last trimester. They found no differences in the first two trimesters. They also found that, overall, women admitted to the program in the first trimester did better than women admitted later, in terms of rates of opioid, cocaine use and compliance with urine testing.

Ward et al. (1998) point out that menstrual irregularities among heroin-dependent women have given rise to the myth that women on heroin are unlikely to become pregnant, and are partly responsible for the lack of emphasis on birth control against unwanted pregnancies. The early symptoms of pregnancy may be mistaken for heroin withdrawal or harmful contaminants that may further delay heroin-dependent women seeking prenatal care and substance abuse treatment.

5.5 Effectiveness of Substance Abuse Treatment for Women

Information providing guidance on effectiveness of women's treatment that is based on strong empirical research continues to be lacking (Health Canada, in press 2000b). Many of the studies lack a randomized design and employ small sample sizes that limit analysis (Howell et al., 1999). To illustrate, Lightfoot et al. (1996) conducted a review of substance abuse treatment for women, with particular reference to the previous five years. The majority of the 211 studies were descriptive, with seven (2%) of the studies specifically examining treatment effects for women using randomized trials, and seven studies using non-random assignment or comparative treatments. Other reviews have found that most of the literature on women's treatment comprises non-controlled clinical and descriptive studies (Institute of Medicine, 1990), discussions on barriers to treatment, and expert opinion on optimal treatment (Health Canada, in press 2000b).

The relatively few studies that have investigated treatment outcomes by gender tend to show no difference in outcomes between female and male alcohol-dependent persons in traditional treatment programs (Lex, 1990; Walitzer and Connors, 1997). Walitzer and Connors (1997) speculate, however, that those who overcome the various barriers facing women, (i.e., the stigma, family and child care responsibilities, lack of identification and referral by gatekeepers, predominantly male treatment programs, and lack of support from those close) may be more distressed or have greater alcohol dependence that motivates them and differentiates them from women who do not receive treatment. Whether this is so or not, there is a commonly held contention that male and female alcohol-dependent persons differ on important dimensions regarding symptoms and treatment needs. Many client satisfaction studies and discussions by experts call for separate treatment facilities or groups for women, as many women in treatment programs are victims of physical and sexual abuse, and need supportive environments where these issues can be explored (Finkelstein, 1993; 1994). Dahlgren and Willander (1989) compared 100 women attending a specialized clinic for women with 100 women in a regular program, and found the clinic group showing fewer social and alcohol problems at follow-up.

While empirical support for the view that women-only treatment facilities are more effective is limited, there is a consensus that has led to the development of female-specific treatment programs (Walitzer and Connors, 1997). An important issue in determining treatment effectiveness is identifying the outcomes that are worthwhile and can be measured. Several investigators suggest that discussion of effectiveness in women's treatment be reframed to give greater prominence to intermediary measures, such as self-efficacy, stress management, and decision-making, rather than simply abstinence measures (Health Canada, in press 2000b; Lieberman, 1998a).

The Center for Substance Abuse Prevention supported a number of programs under the Pregnant and Postpartum Women and Infants (PPWI) granting program that together concluded that programs showing effect on these intermediary measures have a greater and longer lasting impact on the quality of women's lives than programs that demonstrate only a short-term period of abstinence (Lieberman, 1998b).

5.6 Effectiveness of Treatment for Pregnant Women with Substance Use Problems

In their review of this literature, Howell et al. (1999) noted that research on treatment efficacy for pregnant women is sparse and shares the same design weaknesses as women's treatment research generally. There is no clear evidence of any treatment setting being superior to others. Schrager et al. (1995) compared the birth outcomes of over 700 women who had used one of four publicly funded services (either residential treatment only, outpatient treatment only, residential and outpatient, or minimal treatment) and found that women who received only residential treatment had poorer birth outcomes than women in the other programs. Kaltenbach and Finnegan (1998), in a discussion of prevention and treatment issues for pregnant cocaine-dependent women, note that women who lack stable housing and/or are living in adverse conditions may require residential treatment or the provision of safe housing to accomplish and maintain abstinence during pregnancy. Apparent from the literature is that non-traditional settings need to be considered, given that many women have less interest in "formal" substance abuse treatment. Klein and Zahnd (1997) note the role that public health, social services and criminal justice agencies can play in ameliorating substance abuse in ways that may not be referred to as "drug treatment".

Because women with substance use and other serious health issues are typically challenging to engage and retain in treatment, much of this literature focuses on factors affecting program completion. This line of investigation has also been spurred by the finding that women who complete treatment have a greater likelihood of reducing their substance use than those who do not complete treatment (Howell et al., 1999). However, many of the associations being made in this literature between program enhancements, retention and positive outcomes cannot be confirmed without further studies that control for client characteristics, because it may be that clients who remain in treatment differ on other dimensions (for example, are more motivated) (Roberts and Ogborne, 1999a).

In a randomized clinical trial using a small sample of cocaine-abusing women, participants who had their children living with them remained in a long-term care therapeutic community longer than those women who did not (Hughes et al., 1995). In another controlled study, Strantz and Welch (1995) found that new mothers were significantly more likely to remain in an intensive day treatment program (similar to residential, but returning home each evening) than in a standard outpatient program.

There is increasing evidence from demonstration projects of the US Pregnant and Postpartum Women and Infants (PPWI) granting program that perinatal substance abuse treatment for high-risk women can have a positive impact (Eisen et al., 2000). Eisen et al. (2000) reported on the impact of nine community-based PPWI programs using a quasi-experimental design and a sample of 658 women. Participating women received either case management and referral to services or day treatment; these women showed significantly reduced substance use between intake and delivery, whereas comparison women did not. It appeared that, after controlling for other possibilities, the amount of substance abuse programming (i.e., the number of contact hours with the program) received prior to delivery was the major factor in the reduction of substance use among participating women.

As a result of these and other findings from PPWI projects and other US government granting programs, a strong consensus among experts is emerging concerning important elements of substance abuse treatment in the perinatal period. The following themes arose in evaluations of these programs as contributing to successfully reaching pregnant substance users and retaining them in care.

5.6.1 Respectful Service Philosophy

In launching programs designed specifically for pregnant women using substances, program planners have identified as foundational to engaging women in treatment, the need to address women's shame and guilt experienced about their use, their feelings of loss of control over their lives, and their mistrust of the systems scrutinizing them. In this context, programs have "shifted away from stigma, blame, confrontation and shame" (Creamer and McMurtrie, 1998) towards an empowering and strengths-based approach (Mosley, 1996; Grant, 1996; Paquet, 1998; Garm, 1999; Rosensweig, 1998). Implicit in a respectful, non-judgmental approach is an openness to allowing women to set goals for improving their health that may not give immediate priority to substance use issues and when they do, accommodating goals of reduced use rather than immediate abstinence (Rosenbaum and Irwin, 1998). The programs, Breaking the Cycle in Toronto and Sheway in Vancouver, employ a non-judgmental harm reduction approach in their work with substance-using pregnant women experiencing very significant challenges.

The Sheway Project is an outreach program established in 1993 in the Downtown Eastside of Vancouver, one of Canada's poorest neighbourhoods. Sheway takes a woman-centred, harm-reduction, culturally-focused approach to providing services, which are offered on an outreach and drop-in basis from a storefront in the heart of the Vancouver's Downtown Eastside. Sheway provides both practical support to women to address basic needs (such as daily hot nutritious lunches, food coupons and food bank hampers, nutritional supplements, bus tickets, formula, and diapers) and professional services offered by a multidisciplinary staff, some of whom provide onsite assessment and care.

In a recent evaluation of Sheway, significant increases were found in a number of areas, including the proportion of women who: accessed pre- and post-natal care on a range of health and social issues, made significant improvements in their nutritional status, made significant improvements in their housing situation, and retained custody of their children. The evaluation found more modest success in terms of the proportion of women who had accessed alcohol and drug treatment services, had stopped substance use, and/or were stabilized on methadone over time (Poole, 2000).

On this same theme, a number of programs have recognized the importance of peer counsellors in engaging women in treatment. The SISTERS program in New York City utilizes peer counsellors from the community who have been sober for at least a year, trained for three months and under clinical supervision. In a non-controlled comparison of satisfaction rates between clients of a standard professional service and the peer-counselling program, clients of the latter program were twice as likely to cite their counsellors as the most helpful element of treatment as members of the comparison group (Sanders et al., 1998).

5.6.2 Providing Comprehensive and Practical Care

A second theme regarding the provision of treatment to women with alcohol and other drug problems during pregnancy is the success achieved when programs provide a "comprehensive array of resources that go beyond traditional program offerings" (Brindis et al., 1994). Instead of focusing narrowly on change in substance use patterns, programs have found it useful to combine alcohol and drug treatment with other services such as prenatal care, other medical care, parenting education, family planning services, nutritional support, advocacy on housing needs and counselling on violence and relationship issues (Volpicelli et al., 2000; Lieberman, 1998a; Creamer and McMurtrie, 1998; Garm, 1999; Grella, 1996; Kerson, 1990; Egelko et al., 1998; Finkelstein, 1994; Grayson et al. [eds.], 1999; Ryland et al., 1996; Mosley, 1996; Brindis et al., 1997; Namyniuk et al., 1997; Rivadeneira et al., 1998; Whiteford and Vitucci, 1997; Young and Gardner, 1998; Whiteside-Mansell et al., 1999).

To illustrate, among a relatively large urban and rural sample of pregnant women seen at public health, social services or correctional agencies in California, the greatest expressed need was, in descending order, assistance with finances, job placement, housing, getting food, and entering educational programs. Relatively few of these women were interested in formal substance abuse treatment (Klein and Zahnd, 1997).

Of the various services needed by these women, treatment for substance use problems is often seen as having the most formidable barriers, so programs often engage women through other avenues. This results in reducing related harmful effects to the mother and child while increasing the likelihood that substance abuse treatment will be considered. Several programs have specifically described the utility of a change-oriented and motivation approach whereby women are actively engaged in choosing the life areas they wish to work on (Grant, 1996; LaFave, 1999).

In some cases, this comprehensive programming has been organized into a "one-stop" multidisciplinary clinic setting (Paquet, 1998; O'Donnell et al., (1997). O'Donnell et al. (1997) describe a comprehensive Mother-Child Intervention model in the US for pregnant cocaine users using a coordinated and single point of access approach to providing prenatal care, early childhood intervention services, substance abuse services, vocational rehabilitation, and parent/family focused social programs. Additional funding also allowed the program to use incentives, such as providing lunch, coupons and donated items for attendance. Involvement in this program resulted in reduced drug use, improved compliance with prenatal care, and improved post-birth outcomes that were similar to no-drug use controls at 12 months.

Central to providing comprehensive care is the provision of practical support, such as transportation to appointments and help with babysitting costs. Numerous studies have found the provision of this practical support to be associated with success in recruitment and retention of mothers (Ashery et al., 1997; Robles et al., 1994; Rivadeneira et al., 1998; Ryland et al., 1996; Laken and Ager, 1996; Brindis et al., 1997; Clayson et al., 1995).

Availability of child care during treatment is a significant issue for women. Hughes et al. (1995), employing a controlled research design with a small sample, found that women who lived with their children during treatment remained in treatment significantly longer than women who did not. In her discussion, Lex (1990) noted that provision of transportation, legal aid, or job counselling appeared to have less effect on treatment outcomes than did provision of child care. In a qualitative study of the perception of treatment effectiveness of 24 women, participants indicated that they want and need assistance in obtaining child care, and when child care services were accessible, participants found this to be among the most helpful services in terms of improving attendance and use of drug treatment (Nelson-Zlupko et al., 1996).

Lanehart et al. (1994) examined which aspects of a comprehensive, individually tailored program predicted substance-free time within the context of an intensive case management program for cocaine-dependent women and found that vocational services, aftercare and residential care were associated with substance-free time.

5.6.3 Interagency Collaboration and Coordination of Services

The range of health, social and support services required by pregnant women when they are abusing substances is daunting for any single agency. Overwhelmingly, the literature points to interagency collaboration and coordination as critical both to engage and retain women in treatment, and to assist agencies in providing the needed scope of care for both the mothers and their children. (Young and Gardner, 1998; Grayson et al. [eds.], 1999; Laken and Ager, 1996; Rivadeneira et al., 1998). As crucial as it is, interagency coordination is also very challenging. Barriers that need to be overcome include elements of programming housed in different locations, programs having separate regulations, long wait-lists for services, differing intake procedures and eligibility requirements (Finkelstein, 1994).

Perhaps the most critical area of collaboration is between the child welfare and substance abuse treatment domains (Young and Gardner, 1998). A key barrier to engaging pregnant women in treatment is the fear of losing custody of their children (Poole and Isaac, 1999). Many authors in the area of child welfare (e.g., Besharov, 1992; Besharov [ed.], 1994) have argued against developing treatment programs that separate mothers from their affected children, noting that women often attempt another pregnancy to replace the lost children, and fail to participate actively in their own treatment because of concerns about their children's welfare. A related area is the foster care component. In California's Options for Recovery projects, foster parents were recruited to meet the particular needs of children who were prenatally exposed to drugs. The programs targeted specific racial populations so that infants could be placed in culturally appropriate homes, provided recruits with respite care for themselves as caregivers and training in caring for substance-exposed infants, and supported involvement of birth mothers in decision making with the foster parents on child care issues (Brindis et al., 1997).

5.6.4 A Broad and Flexible Continuum of Substance Abuse Services

The literature describes the challenges inherent in supporting pregnant women to enter, re-enter and complete substance abuse treatment. A broader array of services - including case management, pretreatment programming, harm reduction programming (such as prescribing of methadone), medical detoxification, short-term intensive programs (day and residential), as well as sober housing and aftercare - is advocated (Brindis et al., 1997; Howell et al., 1999; Laken and Ager, 1996).

a) Outreach

A significant component of alcohol and drug treatment for this population is outreach. Outreach efforts have served effectively to reduce known barriers such as fear, low self-esteem and lack of motivation, while demystifying what is available and what is involved in the various levels of care (Brindis et al., 1997; Garm, 1999; Namyniuk et al., 1997). In addition to street outreach targeted directly to women at-risk, the Dena A Coy program in Alaska has described outreach work as also involving collaboration with referral sites, education of community agencies, and advertisement of programs (Namyniuk et al., 1997).

b) Case management and flexible scheduling

Case management, from a broad, client-centred approach is repeatedly described as a key component of an alcohol and drug system of care responsive to the needs of pregnant women. Laken and Ager (1996) studied the effect of case management services on retention in treatment with a sample of 225 pregnant women in a large US city. Case management services that included home visits, telephone counselling, transportation and advocacy with other professionals by members of the multidisciplinary team were viewed as significantly contributing to retention in treatment. In the Eisen et al. (2000) report of nine PPWI programs, women participating in the case management services fared better than day treatment participants, reporting lower prevalence of any illicit substance use (with other relevant factors controlled).

Flexibility in providing access and in accommodating absences while in treatment has been found to be critical to enhancing retention of pregnant and parenting women who are receiving care. Egelko et al. (1998) describes "the daunting array of competing demands on their schedule (e.g., medical appointments, activities related to their older children in protective custody) to be handled while also meeting the official requirement of attendance (in day treatment programming) five days per week". It is noted that the process through treatment for pregnant and parenting women is not necessarily orderly, but more often takes a complicated cycle of entering treatment, trying different types of treatment, relapse, reunifying with children, completing treatment and maintaining sobriety.

Accordingly, programs emphasize the importance of incremental steps rather than completion of treatment or maintenance of sobriety as the indicator of success. Flexibility regarding the response to relapse is another key component of working with women with substance use problems in the perinatal period. Many programs no longer view relapse as automatic grounds for discharge from treatment. The client is assisted to resume her recovery plan and she is invited to measure success by longer periods of abstinence, fewer relapses, and by improvement on other quality of life measures (Mosley, 1996).

c) Attention to family issues

Programming that integrates women's children and partners in their care has often been found to improve treatment outcomes for women in the perinatal period. An almost universal finding is that women are often unwilling or unable to separate themselves from their caregiver role to attend to their treatment needs. Many programs have found that even when partner relationships are in turmoil, it is critical to support decision making around disconnection or reunification, as a primary task of this period (Egelko et al., 1998; Rivadeneira et al., 1998).

Finkelstein (1996) has described a relational model of women's treatment that acknowledges the importance of relationships in a woman's life and gives priority to helping foster healthy connections within the treatment process. Finkelstein (1996) stresses that "to be effective in helping women, treatment programs must help clients develop models for healthy, mutually empowering, non-destructive relationships". Individual-oriented treatment approaches that do not account for the crucial role of relationships are not seen as promising as family-centred comprehensive treatment models in which families in the broad sense of a community or group of persons closely connected to each other are provided services in a coordinated fashion.

Whiteside-Mansell et al. (1999) evaluated the effectiveness of the AR-CARES program, based on Finkelstein's (1996) adaptation of self-in-relation theory. During implementation, the program was adjusted to address the needs of women with respect to housing, mental health counselling, child care, early intervention for the children and transport. The five-year study employed a quasi-experimental design and found that, while all women in the study reduced their alcohol and other drug use, AR-CARES participants reduced their use to a significantly greater extent than non-participants. The reduced substance use of participants was associated with improvements in birth outcomes and living environments for their infants.

Egelko et al. (1998) examined the effectiveness of adding gender-specific components for pregnant cocaine-using women attending a co-ed treatment program. In addition to attending the co-ed program with a focus on abstinence, women attended either a standard gender-specific component providing elements such as parenting, vocational training, women's health and prenatal care, or an enhanced version of the gender-specific programming with additional emphasis on promoting family re-integration.

Comparisons were made between women who attended the standard gender-specific component and the enhanced gender-specific component (with groups based on time of enrolment in the overall program) as well as with non-perinatal clients attending co-ed treatment during the same time periods. The study found decreased substance use and improved retention for the group treated in the enhanced gender-specific component compared with those treated in the standard gender-specific component.

With a somewhat similar emphasis on family, Walker et al. (1991) describe a program model for women who have given birth to an infant who tested positive for cocaine. The program emphasis was on empowerment of women and a family case management approach, which, as well as addressing drug use issues, promoted bonding to positive female role models, repairing connections to family and children and concrete family building services.

d) Continuing care or aftercare

The literature on continuing care or aftercare for women, particularly pregnant women, is limited. However, clinicians note that continuing contact with and support of the woman following treatment is critically important in increasing the likelihood of long-term recovery, and represents a sound use of resources. This is due to the massive number of issues and lifestyle changes that women typically need to work through following treatment, including: the development of new social support networks, dealing with new roles in their family, relationship issues, learning to anticipate events that precipitate drinking or drug use, dealing with new emotions, and learning to trust others. Continuing care programs use a number of services, including group sessions, individual counselling and phone support, and follow-up to help women as they address these many issues.

5.7 Seattle Birth to Three Program

A program that reflects these themes and has been subjected to strong evaluation is the Seattle Birth to Three Program (Ernst et al., 1999). The study is unique in this literature in that it randomly assigned women to experimental and control groups, matched groups by potentially intervening variables, assessed a range of maternal and child outcomes (not just substance use), and followed women and children for three years, with a low attrition or drop-out rate.

The Birth to Three Program is a comprehensive program for high-risk women in Seattle that employs intensive, long-term case management through paraprofessional advocates that provided emotional support and assisted with connection to community services. Advocates worked with a small caseload of 12 to 15 women at a time. The work of advocates was highly individualized, but reflected relational theory and was concerned with all of the issues facing these women. They did not provide direct services, such as substance abuse treatment or child care, but rather facilitated the women's connection with these services in the community through regular and, as needed, home visits, and active contact with the extended family. This is one of the few programs to incorporate family planning as a form of prevention of FAS and other forms of teratogenic exposure. They encourage women to limit family size in order to cope with needs of the children already in their care.

Clients and their children were evaluated at 4, 12, 24, and 36 months into the program. All evaluations were done by raters who were unaware of the client's status: control versus intervention. Outcome was assessed in five broad categories:

- Utilization of alcohol, drug treatments;
- Abstinence from alcohol and drugs;
- Family planning;
- Health and well being of the target child;
- Appropriate connection to the community.

At recruitment, there were no differences between the 65 intervention subjects and 31 control subjects. Maternal follow-up at 36 months included 92% of the intervention groups and 83% of the controls. Child follow-up was 92% for the intervention groups and 87% for the controls. This follow-up rate is higher than in the majority of studies involving high-risk women, who tend to be transient.

Clients receiving the services of the advocate scored higher than controls on all five aggregate outcome variables at 36 months. Clients with the best outcomes were those most closely connected to their advocates.

Almost half of the intervention group who had had no previous substance abuse treatment had completed inpatient treatment during the three years. Abstinence rates were higher in the intervention group, particularly for those closely attached to their advocates. By the end of the three-year period, 73% of clients reported using a reliable form of birth control and 43% had chosen a permanent form such as Depro-Vera injections or a tubal ligation, compared with 52% and 32% of control women, respectively.

The Seattle program provides tertiary prevention of future drug- and alcohol-affected births by encouraging women to seek treatment for their substance abuse and to use reliable family planning methods, and by connecting them with other health and social services. The connection of the at-risk woman with her advocate was a powerful intervening variable in outcome. Women were most likely to be well connected to their advocate when they shared cultural and linguistic values. The social support provided by the advocate appeared to have empowered the women to make and to sustain positive lifestyle changes (Ernst et al., 1999).

5.8 Other Treatment Modalities

5.8.1 Contingency Management

A treatment model that has been shown to be effective with a number of populations - contingency management - has also shown promise with pregnant cocaine-dependent women. Contingency management involves the use of incentives to systematically reinforce treatment retention and abstinence. Elk and colleagues (Elk et al., 1995; 1998) have used contingency management procedures in several studies in the treatment of cocaine-dependent pregnant women employing both pre-post comparison and random assignment. Though the samples were very small, the results indicated that monetary incentives resulted in decreased cocaine use and better compliance with prenatal care. Seracini et al. (1997) also found increased cocaine abstinence with the use of voucher incentives for pregnant cocaine users. Jones et al. (2000) did not find low magnitude incentives effective in increasing program attendance.

5.8.2 Methadone Maintenance Treatment

Methadone maintenance treatment (MMT) is recognized as the standard treatment for pregnant opioid-dependent women (Ward et al., 1998). Ward et al. (1998) notes that the research evidence has clearly shown that MMT produces better outcomes than not being in treatment for pregnant, substance-using women. Apart from providing a legally manufactured drug at a controlled dosage, MMT can retain women in treatment, reduce health risk behaviours associated with injecting drugs, provide women with access to prenatal care and other services, and reduce the likelihood they will have to engage in prostitution or other criminal activities to support their drug habit. Infants born to methadone-maintained women are also born later and larger for gestational age than those born to opioid-dependent women not in treatment (Ward et al., 1998). However, Jones et al. (1999) also note that many of the studies reporting better outcomes for mother and infant were done in settings that provided comprehensive care, and the conclusions that can be drawn about the role of methadone *per se* in improving birth outcomes are limited.

The importance of comprehensive services in support of MMT has been noted (Jones et al., 1999). Jarvis and Schnoll (1994) identified obstetrical and medical care, education about issues such as parenting, nutrition and addressing of a range of psychosocial issues through individual, group and family counselling. Ward et al. (1998) discuss the need for group therapy for women participating in MMT, as well as the need to consider the pros and cons of family oriented MMT.

Several studies have examined enhanced MMT in retaining women in treatment and in improving treatment outcome. For example, Carroll et al., 1995, in a randomized clinical trial and non-randomized pilot study respectively, compared women in a standard MMT program which, as well as methadone, included weekly group counselling and urine toxicology three times a week. This was compared with an enhanced program that provided weekly prenatal care, weekly relapse-prevention groups, monetary incentives for drug-free urine samples and child care. Though there were no differences in drug use between the enhanced and standard MMT groups, the enhanced group did have a higher rate of prenatal care visits, adequate gestation and high birthweight infants.

Ward et al. (1998) also discuss the need to consider the pros and cons of family-oriented MMT. If a pregnant woman is given priority access to MMT and her partner is not, this may produce conflict because their drug-dependent lifestyle is threatened by the woman's entrance into MMT. Also, if her partner is continuing to use, this presents a high-risk situation for the pregnant woman. However, some clinicians are concerned about involving partners in the same MMT program because of high rates of violence experienced by women with substance use problems (Ward et al., 1998).

5.8.3 Culturally Appropriate Treatment for Aboriginal Women

The report of the National Round Table on Aboriginal Health and Social Issues, *The Path to Healing* (Government of Canada, 1993), advocates a spiritual basis to treatment for Aboriginal peoples. Emphasizing a holistic approach reflected in the medicine wheel, central to the process is rediscovery of cultural and spiritual traditions. Treatment in this context often includes a community-wide approach to healing and recovery that sees other persons in the community, as well as organizations such as Native Friendship Centres, as part of an "extended" family (Van Bibber, 1997).

5.9 Cost Effectiveness of Treatment

Treatment of substance abuse during pregnancy has been shown to be a cost-effective strategy (Svikis et al., 1997). This group from Johns Hopkins compared the cost of treating pregnant women's drug abuse during pregnancy, and the subsequent cost of caring for their infant during the newborn period, with the cost of caring for the infants of a group of pregnant women who did not receive treatment. Infants born to women who received treatment during pregnancy were less likely to require neonatal intensive care and those who did require a stay in a neonatal intensive care unit (NICU) were admitted for shorter stays than those born to untreated mothers. The cost savings from reduced NICU time alone were greater than the cost of treating the women during pregnancy. The average cost of treating a woman ($6,639) as well as her infant ($900) was less than the average cost of an NICU stay for an affected infant born to an untreated mother ($12,183). These authors did not include later costs, such as those pertaining to special education needs of the affected children. Over a life-span, the actual cost savings from reduced costs of providing a panoply of services to the affected offspring alone would be much greater. The authors further noted that many of the women in their study were involved in prostitution and were HIV-positive. Reducing the health risks of these women would result in further cost savings, assuming that women in recovery from alcohol and drug addiction would be less likely to remain in the sex trade.

5.10 Policy and Legal Issues

Pregnant substance-using women may have been more profoundly impacted by alcohol- and drug-related policies and sanctions than other population groups requiring substance abuse treatment. These policies and sanctions include the historical emphasis on treatment models for men, and co-educational treatment as the norm; lack of funding and other mechanisms to resource child care for those attending specialized substance abuse treatment; and civil and criminal sanctions for pregnant substance-using women. In addition, it is only very recently that those who advocate on behalf of women with substance use problems have come together with those who advocate on behalf of children affected prenatally by alcohol or other drugs. The recent Treatment Improvement Protocol on pregnant substance-using women eloquently summarizes the plight of pregnant, substance-using women:

> "Most common, however, is the neglect they experience from health care and service delivery systems. The painful repercussions of the prosecution and neglect of pregnant, substance-using women and their children can be seen in shelters for battered women, among homeless populations, and in foster homes and child welfare institutions across the country" (Mitchell et al., 1995, p. 6).

Though enormous strides have been made in Canada in the last 25 years in recognizing the need for special programming for women, many women still enter a treatment system that may not have the resources to address their special needs. For pregnant substance-using women, the lack of appropriate services is even greater.

Both in Canada and the US, lack of child care presents a major barrier affecting access to treatment for women (Health Canada, in press 2000b; Blume 1996). Lack of child care is a major reason why women fail to seek treatment (Brown, 1992), while provision of services for children and child care attracts more women into treatment (Beckman and Amaro, 1986). Particularly given the high rates of historical and current physical and sexual abuse experienced by women with substance abuse problems, a pregnant woman who already has a child may find it difficult to find a suitable family member to provide child care. Even for those accessing non-residential treatment, the options for temporary child care may be limited and financially prohibitive. However, many women are very reluctant to turn to the child welfare system for temporary foster care because of fear of losing custody of their children (Blume, 1996; Health Canada, in press, 2000b).

In Canada, the Yukon has mandatory reporting requirements specifically related to substance use during pregnancy (1986), which is similar to a number of US jurisdictions. In some states, the definition of child abuse or neglect includes prenatal drug exposure, which has led to policies requiring reporting and automatic removal of children exposed to substances prenatally, regardless of whether the mother's substance use impacts on her parenting ability (Blume, 1997; Paltrow, 1998). Poor and racial minority women have been disproportionately affected by such policies (Whiteford and Vitucci, 1997).

Some US jurisdictions have gone even further in requiring mandatory treatment for pregnant women using substances, charging women with a criminal offence related to their use of alcohol or other drugs during pregnancy (Blume, 1996; Whiteford and Vitucci, 1997). In Canada, the recent case of Ms. G. highlighted the issue of mandatory treatment for pregnant substance-using women. However, as in the US, Canadian higher courts have ruled against mandatory treatment of pregnant women.

There are a host of arguments against mandatory treatment and/or the involvement of the criminal justice system as mechanisms to prevent substance use during pregnancy, and in favour of providing comprehensive care addressing a range of health and social issues as most likely to lead to the best outcome for mother and child. The most obvious and serious consequence of a punitive approach is that it will deter women from accessing needed services or from being able to discuss their substance use with health care professionals, leading to a poorer outcome for mother and child (Murphy and Rosenbaum, 1999; American Academy of Pediatrics, 1995; Paltrow, 1998; Whiteford and Vitucci, 1997). Punitive approaches also fail to recognize and address the complexities of the lives of many woman who are pregnant and using substances. These may include lack of a support system, unstable environments, homelessness, poor parenting, mental illness, partner substance abuse, family violence, poverty (Clarren, 1999; Mitchell et al., 1995; Murphy and Rosenbaum, 1999), as well as, of course, the lack of appropriate services.

Jails do not provide a substance-free environment or the appropriate prenatal care and substance abuse treatment that would seem to be the rationale for a criminal justice approach. As the American Academy of Pediatrics states in its 1995 policy statement on Drug-Exposed Infants (American Academy of Pediatrics, 1995), "There is no evidence that these latter sanctions (criminal penalties on women who use drugs during pregnancy) prevent *in utero* drug exposure or help drug-exposed children". Finally, it has been pointed out that mandating treatment for pregnant women would introduce social control of women based only on the fact of pregnancy (Blume, 1996).

The earlier in the pregnancy a woman can access appropriate care, the greater the chance of a healthy pregnancy and outcome for the infant. It is not known to what extent provincial/territorial government policies give priority to pregnant women and link with other needed services such as prenatal care. However, 166 providers in the substance abuse treatment database of the Canadian Centre on Substance Abuse report that they provide priority access to pregnant women (Roberts and Ogborne, 1999b). For example, the Children's and Women's Health Centre of British Columbia has developed a protocol for admission of pregnant substance-using women that, along with concerted training, has improved access to care for this population (Children's and Women's Health Centre of British Columbia, 1999). The issue of priority access may be particularly crucial for women requiring MMT.

The requirement for training as different professions and systems come together to provide comprehensive care to pregnant substance-using women is crucial. The medical, child welfare and substance abuse treatment systems may have different agendas and understanding of issues, such as reporting requirements regarding suspected child abuse and child custody, confidentiality, expectations regarding recovery from a substance use problem, and the most effective methods for ensuring a healthy outcome for mother and child.

5.11 Summary

In conclusion, though much of the pregnant women's treatment literature is qualitative in nature, a growing number of scientific studies is confirming expert clinical opinion in the following areas: the need to engage women prenatally, and to provide a comprehensive, coordinated and consistent range of prenatal and substance treatment services, including emphasis on promoting the mother-child bond and other important family relationships in a woman's life. As well, there is some research and a consensus among experts that the provision of adjunctive services, such as child care, transportation, housing, and vocational rehabilitation, is of critical importance. Case management is an effective way of providing for the various health and social needs of pregnant women who use substances. In addition, there is some evidence that providing incentives, such as money, vouchers or gifts, may increase compliance with care and reduce cocaine use. Finally, there is no indication that punitive measures against pregnant substance-abusing women are effective.

5.12 Best Practice Statements

> *There is moderate evidence and a consensus among experts that combining prenatal care with other services, including substance abuse treatment, shows positive outcomes for women with substance use problems and their newborn child.*
>
> *There is moderate evidence and a consensus among experts that gender-specific substance abuse treatment is more effective for women than programs serving both men and women.*
>
> *There is some evidence and a consensus among experts that treatment services employing a respectful, flexible, culturally appropriate and women-centred approach that is open to intermediary harm reduction goals, based on client circumstances, are effective in engaging and retaining women in supportive programming and in improving the quality of their lives.*
>
> *There is some evidence and a consensus among experts that services with a single point of access addressing the range of social and health needs of pregnant women with substance use problems (e.g., assistance with transportation and child care, education, vocational training, job placement, housing, getting food, income support, and help in accessing health care and mental health services), through collaboration between relevant service providers, are effective in engaging and retaining women in treatment.*
>
> *There is strong evidence that intensive case management or coordination services that advocate for women can be effective in promoting family planning, access to substance abuse treatment, retention in treatment, reduced consumption and connections to community services for high-risk pregnant women.*

There is some evidence that a contingency management approach is effective in reducing cocaine use and increasing attention to prenatal care among cocaine-dependent women.

There is moderate evidence that providing Methadone Maintenance Therapy (MMT) in the context of comprehensive care has a positive impact on the health of mothers and birth outcomes for mothers who are opiate-dependent. Priority access to MMT for pregnant women and program components that address barriers to treatment should be considered in program design. Guidelines for methadone dosage and regimen should take into account changes in methadone metabolism that may occur in the later stages of pregnancy.

There is no evidence to support the use of punitive measures, such as mandated treatment, as being effective in improving maternal and fetal health. A consensus among experts suggests that such measures deter pregnant women from seeking needed services.

6. Identification of FAS and Related Effects

For the purpose of this report, "Identification" encompasses screening, referral and case management activities by various professionals (e.g., public health nurses, teachers, social workers) as well as expert diagnosis of individuals (newborns, children, adolescents, adults) affected by a mother's use of alcohol during pregnancy. Effects in children caused by prenatal use of cannabis, opiates, cocaine, or inhalants are much more limited and are most likely to be noted in newborns.

6.1 Prevalence of FAS and Related Effects

Estimates on the prevalence of FAS and related effects vary widely, depending on the diagnostic criteria used, the method of case ascertainment, and the population surveyed. Obviously, use of more rigorous or narrower criteria, such as counting only cases of FAS and not including partial syndromes, will yield lower prevalence rates. As would be expected, population-based studies yield lower estimates than do studies that have investigated specific communities or groups, as these communities and groups typically choose to participate because of a concern with high rates of substance abuse during pregnancy in the community. Both of these kinds of studies have been conducted in Canada, predominantly with Aboriginal populations. Prevalence of FAS and FAE is poorly understood in Canada.

The population-based prevalence model uses the pre-existing data of a population to estimate the incidence of FAS. Two such studies have been published in Canada. Asante and Nelms-Matzke (1985) surveyed children in northern British Columbia and the Yukon. The authors estimated the rate of FAS and possible alcohol-related effects at 46 per 1,000 Native Canadian children in the Yukon and 25 per 1,000 in British Columbia. They further estimated that 51% to 66% of all children in special education with learning disorders in the study regions were exposed to alcohol *in utero*. Habbick et al. (1996) used a database in the Department of Pediatrics, Royal University Hospital in Saskatoon, to estimate the prevalence in the province of Saskatchewan. This study yielded prevalence rates that were close to worldwide estimates of FAS (i.e., 0.5 cases per 1,000 live births). Habbick et al. (1996) only included cases of full FAS, using the US Institute of Medicine (IOM) criteria for FAS with known exposure history. They acknowledged that the prevalence of the full spectrum of alcohol-related conditions is likely to be 3-5 times higher than that of FAS alone. The problem with this model of ascertainment is that it relies on the assumption that all affected cases will be diagnosed and counted. Thus, this model is prone to under estimating the prevalence of FAS, as undiagnosed cases cannot be counted.

"Captive" community studies in which a community invites researchers into the community to investigate the prevalence of FAS and related effects, have documented very high rates of FAS (up to 1 in 4 pregnancies) (Robinson et al., 1987; Williams et al., 1999; Godel et al., 2000). In this type of study, the researchers visit a small community and examine every child within an age range, making blind diagnoses of affected children. For example, Robinson et al. (1987) closely examined children and mothers in an isolated community in northern British Columbia and found that 14 of 116 children below the age of 18 had FAS and 8 had FAE, representing an unexpectedly high prevalence of 190 per 1,000 for FAS and related effects.

While the results of these studies cannot be generalized to other Canadian communities, they can contribute greatly to a local understanding of need and to appropriate steps being taken. This requires careful thought on the part of the community and investigators, as pointed out by Chudley and Jones (2000). Reports of high rates of FAS and related effects will likely be accompanied by various emotions on the part of community members that will need to be addressed before other steps towards improving community health can be taken. Supporting a broader view of the role of research, Gilchrist (1997) calls for an end to research that tends to objectify Aboriginal communities and a move towards models that develop knowledge useful to self determination. In a similar vein, Kowalsky et al. (1996) have suggested guidelines for researchers working with Aboriginal communities, based on FAS-related studies conducted by the authors in northern Canadian communities.

There is no reliable Canadian prevalence figure available, for FAS, for the spectrum of alcohol-related conditions, or for alcohol and other drug-related conditions together. The only population-based estimate is from Habbick et al. (1996) of 0.5/1,000, but these authors acknowledged this was likely to be an underestimate and unreliable. The studies by Robinson et al. (1987); and Williams et al. (1999) indicate that there are specific Canadian communities where the prevalence is much higher. Like many other complex social problems, the consequences of prenatal exposure to alcohol and other substances are not evenly distributed throughout the country.

In the US, the Centers for Disease Control and Prevention have used newborn birth defect registries to estimate the incidence and prevalence of FAS and related effects (Cordero et al., 1994). While these studies have been useful in documenting the differences in the rates of FAS and related effects across racial groups in the US, they are known to underestimate the rates of the condition, as most cases are not diagnosed at birth (Little et al., 1990).

Abel (1998b) points out that prospective/active surveillance systems yield the most accurate estimates of the prevalence of all birth defects, including FAS. He reviewed 29 studies from around the world that used this methodology to document the incidence of FAS. From these studies he extrapolated a worldwide incidence figure of 0.97/1,000 of FAS, which ranged from a low of 0/1,000 from several countries to a high of 3.9/1,000 in Detroit. This figure was only for cases of FAS and did not include cases that did not meet the criteria for the full syndrome. This estimate is comparable to the figure of 0.5/1,000 generated by Habbick et al. (1996), adding credence to their figure as a minimal population-based estimate for a Canadian province.

A number of limitations to this approach pertain to difficulties in diagnosis, and include under-diagnosis, a lack of recording of the diagnosis in medical records, the possibility of stereotyping populations, inclusion of a limited population subset (for example, only infants), and a restricted case definition (Cordero et al., 1994; Little et al., 1990). To illustrate the challenge, some affected newborns may have only subtle facial abnormalities, unapparent central nervous system deficits and normal birth weight, and will be difficult to identify using a restricted case definition (Cordero et al., 1994).

6.2 Guidelines for Diagnosis of FAS and Related Effects

FAS was first reported by Lemoine et al. (1968) in France and then independently identified by Jones and Smith (1973) in Seattle. Jones and Smith coined the term FAS to emphasize the preventable nature of this birth defect. Although the term has enjoyed widespread acceptance, it is not without its critics. Abel (1998c) has recently proposed the term fetal alcohol abuse syndrome to replace FAS in order to emphasize the fact that alcohol abuse (i.e., either heavy per-occasion drinking, or frequent drinking) rather than alcohol consumption causes FAS.

In 1996, the US Institute of Medicine (IOM) (Stratton et al. [eds.], 1996) proposed a revision of the diagnostic criteria for FAS and other alcohol-related effects to reflect current knowledge of the field. The committee recommended five major diagnostic categories:

1. Fetal Alcohol Syndrome (FAS) with a confirmed history of maternal alcohol exposure requiring evidence of facial dysmorphology, growth retardation, and central nervous system (CNS) dysfunction;

2. FAS without confirmed maternal exposure requiring evidence of facial dysmorphology, growth retardation, and CNS dysfunction;

3. Partial FAS (pFAS) requiring a confirmed history of prenatal alcohol exposure, facial dysmorphology, and either growth retardation or CNS abnormalities;

4. Alcohol-related birth defects (ARBD) to denote the presence of congenital anomalies (e.g., cardiac, skeletal, renal, ocular, auditory) known to be associated with a history of prenatal alcohol exposure;

5. Alcohol-related neurodevelopmental disorder (ARND) requiring a confirmed history of prenatal alcohol exposure and evidence of CNS abnormalities.

The changes were proposed to differentiate between those cases where maternal exposure could be confirmed and those for whom the exposure history was unclear. For children in the foster care system, foreign adopted children (Aronson, 2000), and for fostered or adopted adults, information regarding prenatal exposure is often uncertain or unavailable. By providing a category of FAS without maternal history, the diagnostic dilemma that occurred when the history was not available was addressed (Stratton et al. [eds.], 1996). This classification scheme is intended to stimulate further research, both animal and human, into the teratogenic effects of alcohol, while adding clarity to the field. These diagnostic criteria are intended to be applied across the life-span. There are no published guidelines that specify changes to the diagnostic criteria by age. As yet, there have been no independent evaluations of these criteria.

One important change in the Institute of Medicine's 1996 nomenclature is the elimination of the term fetal alcohol effects (FAE). This term has been widely criticized (Aase, 1994; Abel, 1998b) for lacking specificity and sensitivity. The IOM proposed the term "partial FAS" to further delineate the diagnosis of those with confirmed alcohol exposure history and some, but not all, of the anomalies. One of the expectations was that this delineation of a diagnosable condition would lead to eligibility to receive services, such as special education and welfare in the US. Abel (1998a) has been critical of this approach, fearing that it will lead to over-diagnosis of any child whose mother drank at any level during pregnancy. Abel (1998a) also warns that over-diagnosis of partial FAS may inhibit diagnosis of other potentially treatable syndromes. What remains a difficult and controversial issue is the identification of partial FAS without confirmation of maternal drinking.

Astley and Clarren (2000) also criticize current clinical guidelines, suggesting that terms such as FAE, ARBD and ARND inappropriately imply alcohol exposure to be the sole cause of anomalies in a given individual. With the likely exception of facial phenotype, the various physical and cognitive-behavioural anomalies associated with alcohol exposure are not caused only by alcohol exposure. They call for new diagnostic terms that more finely document the variability in exposure and outcomes, and do not imply alcohol as the sole causal agent.

Attempting to address this need for more clinical precision to fetal alcohol-related diagnoses, particularly in cases where the typical anomalies are not extreme, Astley and Clarren (1999) have proposed a more elaborate system that introduces objective, quantitative measures to assist in diagnosis. The system uses the numbers 1 to 4 to convey the magnitude of expression in each of the four key diagnostic domains: growth; dysmorphology; central nervous system dysfunction; and alcohol exposure; and yielding 256 possible 4-digit diagnostic codes and corresponding clinical names.

The authors claim that the approach better characterizes the full spectrum of disabilities of alcohol-exposed individuals, and documents the presence of alcohol exposure without judging its causal role. This system can be added to the IOM system to yield a more precise analysis. Data on the utility of the approach for different age and population groups are not yet available, so it remains to be seen whether this more complex system will be effective.

6.3 Identification and Diagnosis Through the Life-Span

Many authors (e.g., Streissguth, 1997; Abel, 1998b; Gardner, 1997) have emphasized the need for early identification and diagnosis in order to prevent future affected pregnancies and to refer the infant to appropriate services quickly. However, newborn diagnosis is difficult because the specific facial features characteristic of the syndrome may not be apparent until the second year and beyond, and behavioural deficits are more difficult to measure at this point (Gardner, 1997; Aase, 1994). Aase (1994) also points out research that suggests only 70% to 75% of children eventually diagnosed with FAS will experience prenatal growth retardation. Nevertheless, identification in infancy is possible through attention to growth measures and to common manifestations (i.e., feeding problems, irritability, and unpredictable patterns of sleeping and eating) that may be due to withdrawal from alcohol and make the baby hard to care for (Aase, 1994; Stratton et al. [eds.], 1996). A susceptibility to other common birth defects, for example, congenital heart disease, cleft lip and palate, anomalies of the urinary tract and genitals, spina bifida and ocular anomalies, may support (rather than define) a diagnosis (Aase, 1994; Stromland, 1990). Breast-feeding by a currently drinking mother can produce heightened activity in the infant that would need to be distinguished from the effects of prenatal use (Mennella and Gerrish, 1998). Identification of FAS or related effects in an infant is greatly facilitated by knowledge of the mother's alcohol use history, which is best gained through routine, prenatal screening of the mother for alcohol use (Hankin and Sokol, 1995; Russell et al., 1996; Cherpitel, 1997). Meconium (the stool passed by a newborn) testing may be helpful in supporting prenatal screening. While cocaine and other drugs of abuse can be measured in neonatal hair, alcohol cannot. A recently developed meconium test detects by-products of alcohol – the fatty acid ethyl esters – and they reflect maternal history of drinking in late pregnancy (G. Koren, pers. com., 2000).

The facial features associated with FAS are thought to become more recognizable in the pre- and early-school period. In addition, alcohol-exposed children present a number of behaviour patterns that can support identification. These children are affectionate, but very active, flighty, distractible, having poor memory and short attention span - traits that are comparable to children with attention-deficit hyperactivity disorder (ADHD) (Nanson and Hiscock, 1990; Streissguth, 1997; Coles et al., 1997). Important manifestations of central nervous system dysfunction are mental retardation and/or learning disabilities (Conry, 1990; Kerns et al., 1997; Mattson and Riley, 1998).

Children with FAS appear to have deficits in language and speech; however, findings in this area have been mixed. While vocabulary may be adequate, higher-order skills such as comprehension and understanding of semantics and syntax are less developed (Stratton et al. [eds.], 1996; Streissguth et al., 1994). One reviewer termed this pattern "social but dysfunctional communicative interaction" (Abkarian, 1992).

As the child moves into adolescence, identification based on dysmorphology and growth is not straightforward, because many of the physical characteristics of FAS, such as the facial features, become less prominent and more difficult to recognize (Gardner, 1997). There is evidence of catch-up growth for some with earlier slenderness giving way to obesity, particularly in affected girls (Jacobson, 1998; Streissguth, et al., 1991). However, some authors (e.g., Habbick et al., 1998; Day et al., 1999) have presented data to suggest that the growth retardation persists over time.

While physical features evolve, cognitive and behavioural deficits generally endure with age (Mitchell et al., 1995). In fact, behavioural, emotional and social problems can become more pronounced, even when the home environment changes for the better (Jacobson, 1998). Cognitive-behavioural deficits manifest themselves in difficulties with abstract thinking, judgment and problem solving, which in turn give rise to learning, academic and social problems (Mattson et al., 1996; Stratton et al. [eds.], 1996; Aase, 1994). Steinhausen et al. (1993) in a longitudinal study with a large sample, found a number of psychological and emotional problems to persist from pre-school to late school stages among children with FAS, even in the absence of intellectual handicap. Streissguth et al. (1991) suggest that adaptive behaviour and social judgment are impaired to a greater extent than intellectual functioning. Deterioration in these areas may, to some extent, be due to "secondary disabilities" that are not specifically caused by the teratological effects of alcohol, but arise from difficult experiences and inappropriate care during childhood (Streissguth, 1997).

Identification in adults is particularly challenging. It is less clear how the physical markers of the syndrome change with age. If catch-up growth does occur in some individuals, then the establishment of a diagnosis will be problematic after the adolescent growth spurt has been completed. Similar issues exist with diagnosis by way of dysmorphology in adults. Streissguth et al. (1991) published sequential photographs of the same individual in infancy, childhood, and adulthood, which suggested that the facial characteristics of FAS are more subtle and difficult to detect in adults. Astley and Clarren (1999) include growth norms up to 18 years of age and psychometric tests that are applicable to adults.

6.4 Issues in Identification and Diagnosis

Broadly understood and applied diagnostic criteria are basic to advancing FAS-related activity in this country. Yet, diagnosis is not straightforward for a number of societal as well as clinical reasons. Alcohol use by women, particularly pregnant women, remains stigmatized. The stigma and consequent bias among some medical professionals may result in a fear of labelling the mother and child, with diagnosis not even being considered in some populations, or in a hesitation to apply the label, believing that the various manifestations of FAS can be dealt with just as effectively without it (Cordero et al., 1994; Gardner, 1997). For the same reason, pregnant, alcohol-using women are unlikely to report their use accurately.

Clinically, many of the anomalies associated with prenatal alcohol exposure are not unique to FAS and related effects and can be confused with other disorders or conditions, particularly among children with partial FAS, and Alcohol-Related Effects (i.e., ARBD and ARND). Examples of conditions often easily confused with FAS include Aarskog syndrome, fragile-x syndrome, fetal hydantoin syndrome and Noonan syndrome (Astley and Clarren, 1999). Presentation of FAS anomalies varies widely among individuals, with growth retardation seen in most, but not all, diagnosed children, intelligence scores ranging from severely disabled to normal, and a range of behavioural difficulties that generally but do not always co-occur (Aase, 1994; Stratton et al. [eds.], 1996). Consequently, Aase acknowledged that diagnosing FAS in a specific patient is often difficult even for an experienced clinician because the diagnosis depends on recognition of a consistent pattern of minor, often subtle physical anomalies, generalized but disproportionate growth retardation, and non-specific developmental and behavioural problems - some of which change with time and in severity among individuals.

Some contend that the developmental and behavioural patterns are, in fact, quite specific and await more sophisticated testing. Jacobson (1998) suggests that an initial deficit (or deficits) in pre-school children follow a distinct pattern rather than diffuse or generalized impairments.

Supporting this, Janzen et al. (1995), in a quasi-experimental study with a small sample, found that FAS children showed deficits in verbal, performance, language, behaviour and motor skills, but failed to show deficits in visual perception, quantitative or memory skills. However, findings have been at times conflicting on these matters and further investigation is required (Stratton et al. [eds.], 1996).

It also needs to be noted that a diagnosis of FAS does not preclude other problems that may or may not be related to prenatal alcohol use. For example, Nanson (1992) studied children who had both autism and FAS diagnoses and concluded that it was important to account for both in order to intervene appropriately.

Complicating accurate diagnosis still further is the fact that many children who may have experienced prenatal exposure to alcohol may also be victims of abuse and neglect and suffer behaviour problems for these reasons, making it difficult to determine whether the behaviours are due to the child's living environment, the result of the prenatal alcohol exposure, or some combination of the two (Stratton et al. [eds.], 1996).

6.5 Canadian Issues in Identification and Diagnosis

There may be issues in identification with respect to particular Canadian populations. The pattern of facial features proposed by the US Institute of Medicine as markers for FAS, namely short palprebral fissures (short eye slits), flat upper lip, flattened philtrum (the groove between the nose and upper lip), and flat midface, may overlap with racial features, particularly in Aboriginal populations (Aase, 1994). The norms for the measurement of markers such as palprebral fissure length were developed in the US, and may not adequately distinguish facial features found among some in the Canadian population. From studying the effects of prenatal exposure to alcohol among children in a northern Canadian community, Godel et al. (2000) concluded that diagnostic standards need to be established for each ethnic group because of the variance of facial proportions between races. In the meantime, diagnosticians need to guard against over-diagnosis by being aware of local variants in facial features that can occur, and avoid using these alone to support a diagnosis of FAS.

Similarly, the standard growth charts used to assess growth retardation have been developed in the United States. Data are lacking on the applicability of these charts to Canadians. For example, Chudley et al. (1999) reported that normal children in an isolated Manitoba community were typically taller and heavier than standard growth curves would predict. Thus, a child from this community with growth retardation due to prenatal alcohol exposure may be small relative to the other children in the community, but may not be seen as growth retarded on a standard growth chart. There are other anthropological data showing that certain groups of Aboriginal children in BC have a typically larger head circumference compared to North American averages (J. Conry, pers. com. 1999).

Finally, while some of the CNS criteria are objective, such as seizures and structural brain malformations, others may be more subjective, such as the diagnosis of learning disabilities. Psychological tests which have been developed for use with mainstream groups may not be appropriate for children who do not speak mainstream languages or who have not been educated in mainstream cultures. In carrying out an assessment, it is important to ensure that the psychometric tests being used have been evaluated for use with the population group of the child or adult being assessed, and that the examiner is familiar with the cultural characteristics of that community, such as response styles and other behaviours or circumstances that may influence test results.

6.6 Organizing for Identification and Diagnosis

The health care system is in a strong position to provide early identification of alcohol-exposed children during infancy and early childhood. However, in most cases, health care systems do not identify all or most FAS or related cases (Little et al., 1990). Consequently, while this does not generally occur either, others with whom the mother and child have contact (such as child care workers, social workers, addiction workers, speech and language pathologists, educators and correctional workers) with an understanding of FAS and related effects, and knowledge of the availability of diagnostic services, have an important role to play in screening and referring for diagnosis, and in supporting the diagnosis (Hess and Kenner, 1998;

Niccols, 1994; Conry et al., 1997; Jenkins and Culbertson, 1996). Screening for FAS and related effects is particularly called for in some sectors such as the criminal justice system, where there are indications that affected youth and adults are over-represented (Conry et al., 1997).

Currently, there are no fully validated screening tools in common usage to support screening for FAS and related effects. Streissguth et al. (1998) reported on a series of tests of a fetal alcohol behaviour scale to be completed by a person who knows the affected person well. The instrument demonstrated adequate test-retest reliability and produced results that were independent of age, sex, race, IQ and alcohol-related diagnosis. Because it can be administered in a brief period of time, it lends itself to a screening function; however, further study is needed to determine its usefulness with various populations. While this behaviour scale distinguishes the problems of those with FAS from the general population, it has not been shown to distinguish the problems found in FAS with those in other neurological disorders.

Non-specialist physicians and nurses can be of assistance in screening and referral when they obtain information on prenatal exposure history, sequential growth measurements, and help to provide photographs of an affected individual over time (S. Clarren, pers. com. 1999). To support non-specialist medical identification, Astley and Clarren (1995) tested a potentially versatile screening tool based on facial phenotype on the rationale that it is, unlike CNS dysfunction and growth deficiency, specific to FAS. The facial phenotype is characterized by a cluster of minor facial anomalies that include small palpebral fissures, a flat midface, a smooth philtrum, and a thin upper lip. When tested with two racially mixed samples of children, ranging in age from 2 to 10 years, it was found to have high sensitivity and specificity. This screening tool requires further testing of inter-rater reliability and replication in other settings.

Parents' groups have published screening measures (DeVries [ed.], 1999; DeVries et al., 1998), in many cases over the Internet, but these have not been subject to adequate evaluation. Use of these screening instruments can result in confusion because they cite common behaviour problems in children (e.g., lying) that are not related to the diagnosis or occur in normal development and/or in other conditions as well.

Actual diagnosis of FAS and related effects requires a multidisciplinary focus (Stratton et al. [eds.], 1996). Various Canadian and US diagnostic clinics described in the literature have employed multidisciplinary teams, using a physician - typically a pediatrician or geneticist to assess growth and dysmorphology - and a psychologist to assess the behaviours that would support the finding of central nervous system anomalies, such as mental retardation, learning disabilities or adjustment problems (Ridd, 1999; Adrian and Fisher, 1997; Astley and Clarren, 1995, 1999; Li and Pearson, 1996). In some cases, more prominent central nervous system anomalies such as microcephaly or seizures will permit all of the diagnostic categories to be assessed within a medical examination.

Active case finding and screening programs using multidisciplinary clinics serve both to minimize the harmful effects associated with FAS and to raise community awareness. In Saskatchewan, a model of traveling clinics with a specialist team that visits remote communities to assist with diagnosis and with the development of local resources has been used. The FAS team consists of a pediatrician, psychologist, social worker, physiotherapist, occupational therapist, and speech therapist. Local professionals, such as nurses and dieticians, participate as much as possible.

These traveling clinics have been independently evaluated (Adrian and Fisher, 1997). High levels of client and community satisfaction with the model were reported, although some parents reported enjoying the opportunity to leave isolated northern communities to attend appointments in a larger centre, particularly when they have extended families to visit there. Concerns were expressed with the limited numbers of families who can receive services at a clinic and the limited length of the appointments. A similar outreach service delivery model is offered in BC through the Children and Women's Hospital. Patients are seen by a developmental pediatrician, psychologist, geneticist and psychiatrist (C. Loock, pers. com., 1999).

Astley and Clarren (1995, 1999) have described a clinic in Washington DC, emphasizing the need to provide families with information in four broad areas: medical; psychiatric/psychological; educational; and social. The clinic provides diagnosis for all ages, but the majority of patients are between 5 and 15 years of age. This clinic has now been replicated in six other sites in Washington State, and is being replicated in several other states in the US (S. Clarren, pers. com., 1999).

One of these is the Alaskan government, which has conducted and reported on a series of scheduled diagnostic clinics in the larger cities in the state. Children were referred to the clinics from a wide variety of sources: state and community agencies who may have documentation of a child being exposed to alcohol *in utero*; the state's early childhood intervention program; Head Start; native health corporations; the public health nursing program; local school districts; adoption agencies; and mental health resources, pediatricians and family practitioners. Newspaper and radio announcements also encouraged parents to bring children who might meet the screening criteria. Evidence of prenatal alcohol exposure and either growth deficiency or central nervous system impairment were the screening criteria. An expert diagnostician examined those referred. Those diagnosed with FAS then had a comprehensive care plan developed through an interdisciplinary team.

The care plan included attention to the parents and child and the involvement of a care coordinator to support the plan. The clinics diagnosed few new cases of FAS, but identified a number of children and youth with alcohol-related effects that received care plans addressing a number of needs not previously considered (Li and Pearson, 1996).

Also in the US, clinics offer diagnosis of affected children available for adoption from Eastern Europe and Russia, using videotapes supplied by the orphanages where the children live (Aronson, 2000). How these videotapes can be used to assess growth is unclear. Neither is it clear if any independent evaluation of the children is provided if they are adopted in the US. The fate of children rejected because of a video-diagnosis of FAS is also unknown.

In Manitoba, teleconference facilities that link specialists in Winnipeg with physicians and other health care providers in remote communities are being used to develop and distribute the diagnostic resources across the province (Ridd, 1999). As these clinics are just beginning, there are no available data on effectiveness, costs, or client and professional satisfaction.

6.7 Identification of Fetal Drug Exposure

Understanding of the prevalence of children affected by prenatal use of substances other than alcohol (i.e., cannabis, opiates, stimulants, inhalants, hallucinogens) and the nature of the effects is poor for several reasons. Frequently, pregnant women with substance use problems reveal the use of several drugs, making it difficult to identify a primary drug of abuse, amounts used or timing of exposure (Sinclair, 1998; Weintraub et al., 1998). Many studies on prenatal use of other substances, particularly earlier ones, did not control for alcohol and tobacco exposure (Lewis, 1998). Also, it has been difficult to distinguish between the effects of drug use during pregnancy and the effects of poor prenatal circumstances (e.g., little or no prenatal medical care, poor nutrition) (Fried et al., 1992; Hutchings and Fried, 1999). Moreover, community violence, crime, child abuse, neglect, poverty and continued substance use on the part of the mother make it difficult to clarify long-term effects of prenatal drug exposure. Beyond this, self-report is unreliable and toxicology tests are neither widespread nor completely helpful in determining rates of exposure and nature of effects (Weintraub et al., 1998). Nevertheless, the evidence suggests that the continuum of effects can range from minimal to relatively severe (Sinclair, 1998).

Prenatal exposure to other substances does not produce an identifiable pattern of anomalies that has been clearly identified as a syndrome as has FAS (Lester et al., 1996). Because effects range so widely, identification of exposed children often relies on evidence of maternal use of substances. Self-reported substance use estimates have been shown to be unreliable (Jacobson et al., 1991); however, elicited information is more likely to be accurate within a respectful, non-judgmental context (Chasnoff, 1992; U.S. Preventive Services Task Force, 1996; Russell et al., 1996; Lieberman, 1998a). Brief alcohol screening instruments such as the CAGE or MAST can be modified to assess other substance use, but none of these screening tools has been shown to be particularly effective in identifying substance use with pregnant women (Donavon, 1999). The Drug Abuse Screening Test (DAST) is a 20-item self-administration test that parallels the MAST. It can be self- or interviewer-administered, requires no special training to administer, and takes approximately five minutes to complete. Although it has shown validity and reliability, the DAST has not been tested with pregnant women (Caldwell and Burke, 1993).

Consequently, selective screening by a trusted clinician taking a careful maternal history may currently be the best way to screen for substance-exposed children (US Preventive Services Task Force, 1996). Characteristics of the mother that might indicate screening include lack of prenatal care, previous unexplained fetal demise, repeated spontaneous abortion, severe mood swings and precipitous labour.

Although there is no typical profile of a drug-exposed child (Sinclair, 1998), infant characteristics indicating possible prenatal substance use are prematurity, unexplained intra-uterine growth retardation, neuro behavioural abnormalities, urogenital anomalies, myocardial infarction and blood flow restriction (American Academy of Pediatrics, 1998). Newborn withdrawal from a substance may be confused for a common neonatal problem such as colic if the physician is unfamiliar with neonatal effects, or is unaware of the mother's history.

If, based on maternal history or newborn characteristics, prenatal substance use is suspected, urine testing of the newborn can indicate recent drug exposure. Because only recent exposure can be identified, some suggest that negative results should lead to other methods of assessment, such as the meconium (the stool passed by newborns), cord blood, hair samples, and other tissues, that are more effective in determining long-term use of other substances (Koren and Klein, 1997). Meconium testing has been shown to be more sensitive than urine testing and has the advantage of being easier to collect (Ostrea et al., 1992). Marques (1996) reports on research that has found hair testing to be more sensitive in detecting the presence of cocaine in newborns than self-report, urine or meconium testing. These more sensitive tests are not widely available and have not yet been sufficiently validated for screening purposes.

Moreover, clinical history may be more useful than toxicologic testing for identifying newborns at-risk. Among a large sample of drug-exposed infants identified by meconium testing, adverse outcomes were limited to infants born to mothers whose use was apparent through self-report (Ostrea et al., 1992). As these forms of drug testing become more available and validated, they may, in some circumstances, be useful in confirming prenatal substance use, leading to early intervention for the mother and the child. If employed in this context, all forms of testing need to recognize the autonomy and privacy rights of the patient (US Preventive Services Task Force, 1996).

6.7.1 Cannabis

Newborns exposed to cannabis show some of the usual symptoms of neonatal drug withdrawal; for example, fine tremours and exaggerated startle reflex. However, some symptoms, such as hyperactivity and constant signs of distress, have not been observed (Weintraub et al., 1998). Effects beyond the neonatal period reportedly associated with cannabis use are disturbed sleep patterns and effects on visual and auditory development (Weintraub et al., 1998; Fried et al., 1992). Astley et al. (1992) found no consistent patterns of facial features in a sample of 40 children 5 to 7 years of age exposed to cannabis during pregnancy, a finding that is supported by others (Hutchings and Fried, 1999). In an Ottawa-based prospective study controlling for other substances and social and demographic effects, Fried et al. (1992) found no relationship between cannabis use and mental, motor or language outcomes at 12, 24, 36 months; effects noticed at 48 months were not seen at 72 months. Data from this same study suggested that attention deficits may be weakly linked to prenatal cannabis use.

Recently, Hutchings and Fried (1999) have reported on analysis of this same sample of offspring at 9 to 12 years of age and found that, while overall intelligence is not associated with prenatal cannabis exposure, certain higher level cognitive functions may be affected.

6.7.2 Opiates

An opiate neonatal abstinence or withdrawal syndrome (NAS) has been clearly defined, and is estimated to occur in 70% of heroin-dependent mothers (Weintraub et al., 1998) and between 50% to 94% of offspring exposed to opioids or heroin (American Academy of Pediatrics, 1998). The syndrome is characterized by wakefulness, irritability, tremulousness, respiratory disturbances and hyperactivity during the first post-delivery days. Methadone, particularly larger maternal doses in late pregnancy, increases the risk of neonatal withdrawal (American Academy of Pediatrics, 1998). Many obstetricians reduce the mother's daily dosage to less than 20 mg/kg because several studies have demonstrated a lower incidence and decreased severity of neonatal withdrawal with lower dosages. Others are reluctant to wean maternal methadone in late pregnancy due to concern that the mother may turn to other illicit drugs. In fact, some authors suggest increasing maternal methadone late in pregnancy based on lower maternal methadone plasma levels for the same dose (American Academy of Pediatrics, 1998).

Results from studies of longer-term effects of prenatal opiate use have been mixed with some showing the quality of prenatal care and home environment to be more associated with child development than maternal opiate use. In a review of relevant studies, Weintraub and colleagues concluded that although intellectual deficit is mild or non-existent, behavioural abnormalities (e.g., hyperactivity, aggressiveness, lack of social inhibition) may persist into school years.

6.7.3 Cocaine

Prenatal cocaine use is associated with increased risk of spontaneous abortions, premature labour, precipitous delivery, lower birth weight and stillbirth (Chasnoff, 1992; US Preventive Services Task Force, 1996). No studies have substantiated or quantified cocaine withdrawal in newborns (American Academy of Pediatrics, 1998). Neither have the teratogenic properties of cocaine been definitively established (US Preventive Services Task Force, 1996). The vasoconstricting effect of cocaine is thought to be responsible for the drug's possible adverse effects; however, studies on the effect of prenatal cocaine use have produced inconsistent results. A number of these studies have suffered from small samples (with high attrition), and lack of control of other possible socio-demographic explanations for developmental problems (Wasserman et al., 1998). Dow-Edwards (1996) reviewed the animal and human data on prenatal cocaine exposure and concluded that prenatal cocaine did not reliably produce either structural defects or growth retardation. Wasserman et al. (1998), in a large quasi-experimental study controlling for social factors and other drug effects, found no association between prenatal cocaine exposure and intelligence among 6 to 9 year olds, and found that social factors were a better predictor. Recently reported research, much of it sponsored by the US National

Institute on Drug Abuse, is suggesting that there may, in fact, be longer-term effects of prenatal cocaine use that are subtle but real, and involve intelligence, alertness, attention, and fine and gross motor development (Zickler, 2000).

6.7.4 Inhalants

While some researchers have described a fetal solvent syndrome, Medrano (1996) concludes that a discrete fetal solvent syndrome doesn't exist. Effects associated with prenatal inhalant abuse are spontaneous abortion, CNS defects, oral cleft and gastrointestinal anomalies. Many of the effects of prenatal inhalant abuse, including withdrawal, are the same as for alcohol. One difference observed has been "spatulate" fingers with these children (Jones and Balster, 1998). A principal means of identifying recent prenatal inhalant use is chemical odour in the newborn or mother that can persist for several days after delivery (Tenenbein et al., 1996).

6.8 Professional Development Issues

Abel et al. (1993) found experienced biomedical scientists, obstetricians and pediatricians are able to rate FAS with a high degree of accuracy based on facial features. Although high rates of accuracy in the diagnosis of infants have been demonstrated, there is evidence to suggest that many affected infants are not diagnosed in the newborn period. For example, Little et al. (1990) reviewed the records of a large number of newborns discharged from a Texas teaching hospital. Even when all of the diagnostic features were noted in the infants' records, and there was a clear history of maternal substance abuse during pregnancy noted in the hospital records, none of the affected newborns was diagnosed as having FAS while in hospital. In a Saskatchewan study of pediatricians and general and family practitioners, most had either diagnosed FAS in a patient or had had patients with FAS referred to them (Nanson et al., 1995).

So, while effective diagnosis appears possible for those infants with the full syndrome, it is limited by a number of barriers in the health care system, one of which is a lack of relevant information and training (Stratton et al. [eds.], 1996). There is clearly a need for specialized diagnostic information for obstetricians, pediatricians, geneticists, dysmorphologists and psychologists on this issue. Further, training needs to promote better communication and collaboration between obstetric and pediatric staff to establish diagnoses of FAS and related effects, and to provide appropriate medical follow-up for these infants (Little et al., 1990). Issues surrounding the training of professionals for diagnosis after early childhood have not been studied; however, the need is known to be great.

Communication between the medical practitioner and the patient is an issue also. Given that self-report and maternal history are currently the most useful ways of identifying prenatal substance use, it is critical that health professionals learn to create an environment of trust and respect in order to effectively engage and motivate the patient to disclose accurate information and to take appropriate action (US Preventive Services Task Force, 1996).

Other professionals in the school, social service, and correctional systems would benefit from identification and referral knowledge and skills (Conry et al., 1997). An in-service training module to assist early childhood educators in identifying and making appropriate referrals was tested in New York City (1993). While viewed as useful, sponsors were told they needed to articulate the signs and symptoms of prenatal exposure more clearly. In 1995, the FAS/E Support Network of BC prepared a series of six Assessment Handbooks (broken down by life stage from birth to adulthood) to assist non-medical professionals in contact with affected children in determining whether a child should be referred to an expert diagnostician (FAS/E Support Network of BC, 1995). The usefulness of this resource has not been determined empirically.

6.9 Summary

Diagnosis of FAS and related conditions is a complex exercise requiring a multidisciplinary approach. Well promoted diagnostic clinics are relatively common in parts of North America and have been the subject of several studies. These clinics require significant outlay of resources, but have shown some ability to identify new cases of FAS or alcohol-related effects.

Efforts are being made to build on the strong basis provided by the US Institute of Medicines diagnostic framework by designing a more precise and clinically useful system. Nevertheless, unique characteristics found in some of the Canadian population suggest that amendments or cautions would need to be incorporated into any guidelines designed elsewhere if used in this country.

The development of guidelines for the identification of exposure to various other substances of abuse has been impeded by incomplete knowledge of the early and long-term effects of most substances. Currently, a careful maternal history taken by a trusted physician may be the best way to screen for substance-exposed children.

6.10 Best Practice Statements

> *There is some evidence that prenatal screening for FAS is most effective when initiated by routine, collaborative screening of mothers during prenatal care.*
>
> *There is a consensus among experts that the availability of diagnostic services can be enhanced through mechanisms such as specialized training, consultation and support, telemedicine, and traveling clinics.*
>
> *There is a consensus among experts that, in the presence of particular maternal characteristics (including lack of prenatal care, previous unexplained fetal demise, repeated spontaneous abortion, severe mood swings and precipitous labour), or infant attributes (including prematurity, unexplained intra-uterine growth retardation, neuro-behavioural abnormalities, urogenital anomalies, myocardial infarction and blood flow*

restriction), selective screening for maternal substance use by taking a detailed maternal history in a supportive atmosphere can be effective in identifying children affected by prenatal use of substances other than alcohol.

7. Interventions for Persons Affected by Prenatal Substance Use

Intervention refers to activities intended to prevent and reduce harmful effects associated with primary and secondary disabilities among persons exposed to alcohol and other drugs *in utero*. Intervention also aims to promote the development of individuals exposed to alcohol or other substances prenatally, during the various life stages and to support those caring for them. Prenatal exposure to substances, which combined with a difficult postnatal environment, may render the child vulnerable to a variety of negative effects. Due to the range of potential difficulties that can arise, intervention may involve a range of issues, including parenting, family support, school, vocational, young offender, and criminal justice issues.

It is important to note that the amount of research conducted to evaluate the effectiveness of any intervention intended to provide appropriate care and support for individuals affected by prenatal alcohol and other drug use has been quite limited. This is particularly the case with interventions directed to adolescents and adults. In light of this, observations of experts that work with these populations are brought into the discussion to a greater extent.

7.1 Infancy and Early Childhood Interventions

A great deal of neurological development occurs after birth, and if early child-care, nutrition and environment are adequate, much progress can be made by the affected child, particularly when effects are less severe (Coles and Platzman, 1992). Those with an early diagnosis may have somewhat fewer difficulties later on. Consequently, various researchers (Astley and Clarren, 1999; Streissguth, 1997; Streissguth and Kanter [eds.], 1997) have called for early diagnosis and prompt intervention with families of alcohol-affected children to promote the development of these children and to minimize what are termed secondary disabilities. Strengthening this argument, Streissguth et al. (1996) found that among a large sample of adolescents and adults with FAS, those who had a diagnosis before age six had a lower rate of disrupted school experiences, inappropriate sexual behaviour, trouble with the law, substance abuse, and institutionalized care. While the rationale for early diagnosis and FAS-specific intervention is strong, there is currently little empirical evidence pointing to the effectiveness of early intervention for FAS and related effects.

7.1.1 Medical Issues

Infants with FAS particularly, but also with other related effects, have an array of complications that require medical and developmental monitoring and possible treatment. Among these problems, visual, hearing and speech difficulties need to be identified and treated by routine screening prior to school. Hearing problems can contribute to hyperactivity and distractibility that will accentuate the behavioural problems of a child with FAS (Church and

Kaltenbach, 1997). Intellectual and cognitive problems will be aggravated when hearing problems are not identified at an early point. Early language stimulation, attention to speech development and facilitation of fine-motor and perceptual organization have also been suggested as useful interventions at this age level (Phelps and Grabowski, 1992). Specialty care may also be required in neurology, endocrinology, and developmental medicine (Stratton et al. [eds.], 1996).

Although this review was unable to locate empirical research to support the use of a professional, multidisciplinary team to address the range of complex health needs of affected children (Stratton et al. [eds.], 1996), there is a consensus among experts that this is of critical importance. The *Guidelines for Perinatal Care of Substance Using Women and their Infants*, prepared by the Children's and Women's Health Centre of BC (1999), emphasize the need for broad involvement of health care staff, community service agencies and supportive family members in an integrated case management process to ensure optimal care for the mother and child. The Guidelines also underscore the importance of planning for the hospital discharge of the mother and child as early as possible during the prenatal period. In some cases, hospitals provide medical and family support services on site. Because of the expense of hospital stays, there are examples of outpatient facilities in the US for children 1 to 3 months of age that also provide short-term family support services as a bridge between the hospital and the community (Olson and Burgess, 1997).

7.1.2 Family Issues

The quality of a care-giving environment is a very important factor in the development of all children, including those affected by prenatal alcohol exposure (Coles and Platzman, 1992). Studies examining the background of alcohol-exposed children generally reveal a high degree of family upheaval. Numerous children are never cared for by their biological mothers; many natural mothers die when children are very young; and a high number of children begin a pattern of multiple foster home placements (Spohr et al., 1994; Steinhausen et al., 1993).

In Canada, many alcohol-exposed infants are placed in foster or adoptive care, as the biological parents are unable to cope with the demands of an affected infant and their own substance abuse (Habbick et al., 1996). In their study, Habbick and colleagues (1996) found that children entered foster care at two years of age on average, and remained in foster care for an average of over five years. In addition, many children experienced multiple moves.

Similar results were found by Ernst et al. (1999) in the Seattle Birth to Three Program. At the three-year follow-up, many of the children were in alternate custody arrangements, either at the mother's request or because of child welfare concerns. Some parents surrendered their children voluntarily, recognizing that their substance use had a negative impact on the child's development.

Children who remain with mothers or parents who have continuing alcohol problems are likely to experience disruptive, unstable, and possibly abusive home situations that can worsen the child's developmental delays (Abkarian, 1992). Early instability in the child's living situation may also occur due to medical complications and the need for repeated hospitalization and consequent separation from parents during infancy (Niccols, 1994).

Streissguth et al. (1996), in a study of over 400 clients with FAS ranging in age from 3 to 51 years (without a comparison group), presented data that suggest the importance of early, long-term stability. Clients that fared best were those living in a stable and nurturing home, those not subjected to frequent changes of household, or victimized by violence. The study found that multiple placements increased the risk of adverse outcomes for this group and that children needed three years or more in one living situation to benefit from the placement. In a review of early interventions for children with FAS, Weiner and Morse (1994) similarly concluded that a stable, supportive home environment resulted in fewer psychological problems for these children.

Specialized infant development or therapeutic child-care programs may promote some desired stability. In some cases, these programs operate out of the home and work with at-risk parents and children or those who have experienced challenges generally. These programs may be adjusted to better handle the needs of children affected by prenatal substance use and their caregivers. Issues addressed by these programs include coming to terms with the diagnosis, making best use of services, increasing parental knowledge of pertinent factors in the overall growth and development of their child, and learning skills that promote the child's growth (Niccols, 1994).

Initially, these programs often need to work with caregivers on methods to calm the child and to address failure to thrive. Drawing from specific behavioural techniques used with pre-term infants, methods can include swaddling, special ways to pick up, hold, soothe, feed and stimulate the baby, rocking beds and massage therapy (Olson and Burgess, 1997).

Program themes for older pre-school, alcohol- (and other drug-) affected children could include:

- attachment security;
- dealing with transitions;
- expressing feelings and needs;
- verbal self regulation; and
- nutritional, medical and developmental assessment and appropriate therapy.

Although this review was unable to locate empirical studies on effective interventions in pre-school child care, it is commonly recommended that the child care program have a low staff-child ratio, follow structured routines, and regulate the amount of stimulation received by the child. Child-care providers that have a child with FAS benefit from training and extra support (Olson and Burgess, 1997).

In some of these programs, parents can also have access to substance abuse treatment, positive role models, individualized parent training and counselling, and a parent support group. There are, as yet, no outcome studies describing the effectiveness of infant development and therapeutic child care approaches for alcohol-affected children (Olson and Burgess, 1997).

A critical intervention for the family, including any subsequent children, is treatment for the mother's substance abuse problem (see the Tertiary Prevention section). In fact, the recognition of FAS or related effects in a child may uncover the mother's drinking problem and lead to treatment (Olson et al., 1992). Recovery of the biological mother, and if necessary the father, can lead to stability in the home and more positive outcomes for the child. For example, Streissguth et al. (1996) found that living with an alcohol-abusing person for less than 30% of one's childhood was a specific protective factor against substance use by the affected individual among a group of alcohol-affected adolescents followed over a number of years. These data give support to family-centred substance abuse treatment approaches that permit parent access to children, rather than forcing parents to choose between the custody of their children and their own treatment needs.

A promising approach to family-centred treatment is a comprehensive, one-stop model that addresses the treatment needs of the parent(s) as well as the developmental needs of the child. In addition to offering substance abuse treatment and therapeutic child care, these programs facilitate access to other services (e.g., family therapy, personal counselling and parenting education) while generally promoting the need for family support (Coles and Platzman, 1992; Paquet, 1998; O'Donnell et al., 1997).

An example of this model is the Breaking the Cycle (BTC) program in Toronto that has, since 1995, offered comprehensive services through a single-access venue in which mothers and children can receive addiction, health, developmental and parenting services using an integrated, transdisciplinary approach. An evaluation of Breaking the Cycle's first 2½ years of operation indicated that participation in BTC had contributed to healthier birth outcomes, better maternal health ratings, fewer health concerns, fewer parenting breakdowns resulting in separation of children from their mothers, and fewer maternal developmental concerns. Because of their involvement at BTC, young children did not, at the point of evaluation, experience the developmental lags often reported in the literature for those who have been substance-exposed (Paquet, 1998).

There are few evaluation data on the effectiveness of parenting education for a substance-abusing population, although clinical reports suggest that combining substance abuse treatment with parenting information too early in treatment, or in an unintegrated way, can distract the mother from her own recovery (Olson and Burgess, 1997).

In many cases, the mother has experienced physical and emotional abuse in childhood and brings relatively few personal resources to a parenting role, particularly when faced with a child that can place great demands on her (Coles and Platzman, 1992). Consequently, these children are at-risk for neglect, abuse and failure to thrive (Streissguth and LaDue, 1985, Stratton et al. [eds.], 1996).

Various measures have been suggested for stabilizing the situation and enhancing the child's prospects. Streissguth et al., (1997) suggest that strategies for increasing the duration of stay in each placement be made available to biological, foster and adoptive parents.

Olson et al. (1992) suggest the following guidelines in working with substance-using or alcohol-affected parents of children with FAS or related effects:

- understand that the parents may be less skilled than they appear;
- keep parenting advice concrete;
- set up structured parental support;
- have modest expectations about what these parents can do on their own;
- refer these parents for needed treatment and help agencies be sensitive to their needs.

Perhaps the most comprehensive approach to early intervention is the peer support or advocacy model developed in Seattle (Ernst et al., 1999; for further detail see the Tertiary Prevention section). The Birth to Three Program was subjected to a well designed study and utilizes what are referred to as advocates as the centrepiece of the program. An advocate may be a trained professional or paraprofessional who combines a practical, realistic approach with an ability to establish a respectful relationship with parent and child. Most advocates work with a number of families and may be involved in outreach, the provision of information, crisis intervention, providing guidance and feedback, joint problem solving, helping to secure services, and providing encouragement and support to the family.

The work of advocates is highly individualized but generally seeks to: empower and assist women in determining their own goals; encourage recovery; help women to be aware of and to work towards the best interests of the child; provide practical assistance in locating resources and coordinating services; remove barriers for these women; and focus on working with the entire family.

Birth to Three clients and their children were evaluated at 4, 12, 24, and 36 months into the program. Even though the mother was the focus of this intervention, among the various outcomes measured were a number pertaining to the health and well-being of the child.

Health and well-being of the child was high in both the intervention and control groups, reflecting the women's desire to provide optimum care to the child. However, more women in the control group had either voluntarily given up custody of their child or the child had been taken into protective care. All of the children fell below published norms on the Bayley Scales of Infant Intelligence, but were not different across groups.

Bearing in mind that influencing the course of the child's development was not an explicit aim of this postnatal intervention, there was no evidence that it was successful in reducing the developmental delays experienced by the target child. A longer-term follow-up would indicate whether such interventions reduce rates of secondary disabilities such as mental health, legal and substance use problems among children prenatally exposed to alcohol.

When alternatives to family care are required, the data suggest that these alternate placements need to be prolonged rather than brief stays. Adoptive and foster families can be greatly challenged by these children and they find support groups to be helpful for information exchange and dealing with emotions (Weiner and Morse, 1994). It would be beneficial to invest funds into in-home care for the child and respite care for families (LaDue et al., 1992). Information and training for foster and adoptive families on how to promote the development of alcohol-affected children has been recommended as a source of support, as has training for adoption workers and attorneys on issues relating to parental substance abuse (Olson and Burgess, 1997). Unfortunately, none of these interventions has been empirically evaluated.

In Los Angeles County, the TIES (Training, Intervention, Education and Services) for Adoption Program attempts to reduce obstacles to adopting children who have a history of prenatal substance use exposure by focusing on the transition from out-of-home care and for a year after placement. A study examined the experiences of a sample of participants in the TIES Program and found that parents greatly valued the range of services available, which included education on adoption issues, parent counselling, interdisciplinary review of the child's records and child therapy (McCarty et al., 1999).

7.1.3 Psychoeducational Issues

Early education is frequently recommended as an important intervention for preschoolers with FAS (Olson et al., 1998; Abel, 1998b). Children with other developmental conditions such as Down Syndrome, as well as those living in poverty, do benefit from early intervention services (Ramey and Landesman-Ramey, 1998). Children from impoverished families who receive intensive early intervention continue to show the benefits into adulthood (Schweinhart et al., 1993), suggesting that similar benefits may accrue from early intervention for children with FAS and related conditions. However, there are no published studies that demonstrate positive effects of either FAS-specific programming or general early educational intervention for young children with FAS and related conditions.

Some school districts in the US have established preschool programs for children with known prenatal substance exposures. One illustrative program provides self-contained classrooms, careful teaching strategies, high staff-to-student ratios, frequent participation by speech and language specialists, adaptive physical educators, school social workers, psychologists, nurses, and a physician.

Another approach is to support the inclusion of these preschool children in classes with non-exposed peers, again, using strong professional support and low staff-child ratios (Olson and Burgess, 1997).

Coles and Platzman (1992) suggest that the individualized attention that alcohol-affected children need would be more effective when provided through existing programs for developmentally-delayed preschoolers rather than establishing separate programs for such children. They propose that the enhanced program provide aggressive and coordinated case management, information and professional training for alcohol abuse, specific support for both recovering and foster parents respectively, and access to funds necessary to support therapy and intervention. The coordination of these functions may be best accomplished through the creation of a locally-based FAS case coordinator who would facilitate early identification, consistent follow-up, and coordination of therapeutic, educational and training services.

Phelps and Grabowski (1992) suggest the use of clear expectations and reinforcement of appropriate responses to deal with problems of impulsivity common with these children and to facilitate the learning process. The use of medications such as Ritalin to treat hyperactivity of children with FAS has proven effective in some cases and counterproductive in others (Streissguth and Giunta, 1988).

7.1.4 Summary

Infants exposed to alcohol prenatally have complex medical, psychological, and social needs. The medical needs appear best addressed with a professional multidisciplinary approach, although there are no models in the literature to refer to at present. Specialized FAS-or substance-specific elements that build on existing developmental child-care programs are now being developed. Evidence suggests that a stable living environment is particularly important for these children and ways to promote stability, such as training and support services for biological, foster and adoptive parents, need to be studied for effectiveness. Substance-affected children and their families may benefit from intervention programs that coordinate the mother's treatment with specialized child care. There is good evidence to indicate that intensive case management or advocate programs that utilize professionals or peers to work closely to promote the health of the mother and child are effective.

7.1.5 Best Practice Statements

There is a consensus among experts to support the use of a professional, multidisciplinary team to address the range of complex health needs of affected children.

There is some evidence to suggest that a longer-term, stable living environment contributes to more positive outcomes for children affected by alcohol in utero. This may be facilitated by family-centred substance abuse treatment, respite care and other support services, and FAS-specific information and training for birth, foster and adoptive parents.

There is a consensus among experts indicating that child-care programs for children affected by prenatal alcohol exposure employing a low staff-child ratio, following structured routines and regulating the amount of stimulation received by the child may be more effective.

There is some evidence that services offering a single point of access, combining services for the mother with attention to the developmental needs of the child, improve outcomes for the child.

There is a consensus among experts that all persons parenting affected children benefit from and value a range of services to support their parenting of children with FAS and related effects.

There is some evidence from animal studies and studies of children experiencing developmental delay due to other causes suggesting that early educational interventions may contribute to improved outcomes for children affected by prenatal alcohol use, at least in the short-term.

7.2 Later Childhood Interventions

7.2.1 Medical Issues

There is currently some question as to whether the physical health of children with FAS improves in mid-childhood. Loney et al. (1998) reported fewer hospitalizations in school-aged western Canadian Aboriginal children compared to preschoolers; although children with FAS continued to be hospitalized at higher rates than other Aboriginal children. Catch-up growth has been reported, particularly for weight, during this period (Olson et al., 1998). The high incidence of hearing problems with this age group suggest the need for continued routine screening during early school years (Church and Kaltenbach, 1997; Stratton et al. [eds.], 1996). Orthodontic follow up through middle childhood may lead to selected extractions that prevent more extensive oral surgery (Stratton et al. [eds.], 1996).

7.2.2 Family and Social Issues

Several studies suggest that social abilities of children with FAS do not develop normally during this period, particularly skills relating to maintaining relationships (Thomas et al., 1998; Steinhausen et al., 1993; Streissguth et al., 1991). In a study of social skills that controlled for IQ and socio-economic status, Thomas and colleagues (1998) found that relationship skills, that is, the ability to successfully interact with other children, were the most impaired among a number of measures. There is a strong likelihood that, as social demands increase with the years, these impairments become more obvious.

Many Canadian children who are diagnosed with FAS and related conditions spend part of their lives in the foster care system (Habbick et al., 1996; Asante and Nelms-Matzke, 1985). Many of these children experience multiple placements and other disruptions during childhood. For example, Habbick et al.(1996) reported that only 25% of their Saskatchewan sample of individuals with FAS were living with biological parents. Most were in foster care or had been adopted. The average age at adoption was 38.6 months for the 18% of the sample who had been adopted. Seventy-two per cent of the total sample had been in foster care at some point in their lives. The average length of stay in foster care was almost six years. It appears that children who were not eligible for, or placed for adoption at an early age, grew up in the foster care system, often experiencing multiple moves. Similarly, 87% of child welfare agencies responding to a national survey in the US indicated that foster children exposed prenatally to alcohol or other drugs are more likely to experience multiple placements than those not exposed; 90% of respondents indicated these same children are likely to stay in foster care longer than children not exposed (Curtis and McCullough, 1993).

Continuing stability in home life appears to reduce the severity of the behavioural and social problems encountered by an affected child (Streissguth et al., 1996). This appears to be the case particulary between the ages of 8 to 12 years. Streissguth (1997) suggests that this is a critical time when a stable home and parents who know where the child is, who the child associates with, and what they are doing, buffers against adverse outcomes.

Decisions to return a child to his/her biological parents need to be considered very carefully. One pediatrician with extensive experience in this area (J. Snyder, pers. com., 1999) has noted that, too frequently, children are returned to their biological parents to assess their parents' capacity to cope with the additional task of parenting, without assessing the long-term risks to the child if the placement fails. Clearly, if a child remains with the biological mother, it is important that the mother receive appropriate therapy (often for substance abuse and mental illness) and support for parenting her child. Jones (1999) points out that helping agencies need to be aware that biological parents who have a history of alienation from health, educational and social service systems may not present themselves as willing clients. Furthermore, the difficulties in raising children with FAS can be further erarcerbated if the parents, themselves, have FAS.

It is more difficult to find adoptive homes for children exposed to alcohol or other substances than those not exposed (Curtis and McCullough, 1993). It is important that adoptive families be provided with as much information on a child as possible to assist in determining whether the adoption of the child is appropriate for them. Because of the implications involved for the adoptive family, this is particularly important if there is some question of whether the child has been exposed to alcohol prenatally (Edelstein, 1995). There is a need for those involved in recruitment and placement to help parents develop realistic expectations for the child and themselves by providing accurate information on the effects of alcohol and other substance use during pregnancy. It has been suggested that as early as possible, before or after adoption, a complete assessment of the child in terms of medical, intellectual and behavioural issues, is important (Johnson, 1999). Adoptive parents will benefit from ongoing support and advocacy for various medical, educational and psychosocial issues that arise with children prenatally exposed to alcohol and other substances (Edelstein, 1995).

Regardless of the particular circumstances, findings of Streissguth and colleagues (1996) in their study of a large sample of clients with FAS, reinforce the importance of long-term stability in the life of the alcohol-affected child.

While there is a need for others in the community to become involved, families with similar experiences can provide support that can contribute to the needed stability. This support can be through networks with their newsletters and Web sites, for example, the Adoption Council of Canada and the FAS/E Support Network of BC, or books chronicling experiences in raising and developing strategies for supporting a child with FAS, such as *Fantastic Antone Succeeds* (Kleinfeld and Wescott [eds.], 1993) or *Fantastic Antone Grows Up* (Kleinfield et al. [eds.], 2000). Journal articles can also effectively chronicle the experiences of families living with FAS (Gere and Gere, 1998). Although there is no empirical information available on the effectiveness of these forms of parental support, anecdotal reports consistently underscore their importance for caregivers (Olson and Burgess, 1997).

7.2.3 Psychoeducational Issues

Children with FAS and related effects face a new set of challenges when they enter the school system. This is often the time when a diagnosis is first made, perhaps reflecting the visible differences between prenatally alcohol-affected children and their peers. On the other hand, some of these children will not show the dysmorphic effects and will not be so easily diagnosed for that reason. Nevertheless, their behaviour frequently becomes a concern to teachers and parents through this period. Various studies have confirmed that school-aged children with FAS experience more cognitive and behavioural impairments than other children, such as ADHD (Nanson and Hiscock, 1990), lower intelligence levels (Robinson et al., 1987), and inflexible problem solving and deficits in visual/spatial skills (Coles et al., 1997). Reinforcing the importance of partial

FAS diagnoses, the broad impairment in psychosocial functioning has been shown to be the case regardless of whether the children had enough dysmorphic features to obtain a diagnosis of FAS (Roebuck et al., 1999; Mattson and Riley, 1998).

There are no empirical studies that shed light on effective educational interventions; however, a number of researchers, parents and educators have developed strategies for adjusting the learning environment and the content. It is generally recommended that a range of professionals (possibly including educators, speech and language therapists, occupational therapists and educational psychologists) participate in developing and monitoring a thorough psychoeducational assessment that results in an Individualized Education Plan (IEP) tailored to meet the multiple cognitive, academic and psychosocial needs of these children (Phelps and Grabowski, 1992; Phelps, 1995; Stratton et al. [eds.], 1996). The diagnosis of FAS by itself does not qualify for IEP coverage in this country. Children and their families benefit from help in coordinating these various service providers, along with pediatricians, psychologists, and social workers who may be involved.

Concerning adjustments to the learning environment, recommendations include providing a calm and quiet environment, maximizing structure and routine, (Rice, 1992; Alberta Education, 1997; British Columbia Ministry of Education, 1996), low enrolment classrooms, resource rooms or self-contained classroom placement (Streissguth et al., 1991; Phelps and Grabowski, 1992), defining specific work and play areas, keeping work spaces clear and free of distractions, putting materials not in use out of sight, ensuring few distractions, establishing routines that vary little from day to day, providing explicit instructions, using visual aids to reinforce class rules and activities (Weiner and Morse, 1994), repetition and modeling of desired behaviours (Kleinfeld and Wescott [eds.], 1993); and a loving teacher (Rice, 1992).

Suggestions for content include an individualized curriculum with a focus on functional skills for independent living (such as problem solving, arithmetic, social interacting, and decision-making); developing realistic expectations of the child and behaviour management strategies that promote independence; adaptive living, social and communication skills (Burgess and Streissguth, 1992); and role playing to teach logical consequences and appropriate behaviour (Rice, 1992; Winick, 1993).

Many parent resources available on the Internet make similar recommendations. However, it is important to note that, at this point, the effectiveness of particular pedagogical strategies and practices has not been studied with this group of children.

An ongoing problem in this age range that crosses medical, psychoeducational, and social domains is the prevalence of Attention-Deficit Hyperactivity Disorder (ADHD) among children with FAS. While FAS behaviour and ADHD symptoms may appear to be similar, research by Coles et al. (1997) suggests there are subtle differences in the attentional difficulties faced by ADHD and FAS/ADHD children that may require different approaches in addressing these two disorders.

Although many children with FAS have stimulant medication prescribed to address ADHD, few studies have assessed its efficacy. Snyder et al. (1997) used a double-blind study to compare the functioning of a group of school-aged children with FAS on-and-off stimulant medication. This type of design uses each child as its own control, comparing behaviour on-and-off medication, while parents, teachers, and the researchers are "blind" to the child's medication status. Results were mixed. While parents reported significant behavioural improvements in the children while on medication, no improvement was seen while on medication in their measures of attention when undertaking certain tasks. The author suggested that the tasks chosen to measure the drug effects on behaviour were too difficult for the children. In another double-blind study, Oesterheld et al. (1998) found improved teacher ratings of hyperactive behaviour when a sample of Aboriginal children with ADHD and FAS was treated with Ritalin. However, day-dreaming and inattention were unchanged for the four children with FAS while they were on medication.

Both of these studies employed very small sample sizes - 10 in the Snyder et al., (1997) study and 4 in Oesterheld et al., (1998) study - and require replication before any recommendations can be made regarding the widespread use of medication. Underscoring this caution, Snyder et al. (1997) contend that drug treatment of ADHD in children with FAS should occur only after all the other components of a treatment program, such as parental training, and school supports are in place, and further intervention is required.

Wentz (1995) reviewed the 50 US states' criteria for eligibility to receive special education services. A diagnosis of FAS or related effects did not qualify as a condition requiring special education services in any of the 50 states. Both Alberta and British Columbia have published a short fact sheet on FAS for teachers (Alberta Education, 1995; British Columbia Ministry of Education, 1995), but neither discusses the eligibility of children with a specific diagnosis for special education.

7.2.4 Summary

While the physical health of children prenatally exposed to alcohol can improve through this period, their behavioural problems often become accentuated in school and the wider community through these years. The evidence concerning the use of stimulant medication for children with co-occurring FAS and ADHD is mixed, so other interventions should generally be used first before recourse to medication. While specific educational strategies have not been scientifically studied, experts and parent groups are almost universal in calling for low-enrolment classrooms, access to special education services and funding, and structured learning environments.

7.2.5 Best Practice Statements

While there is no evidence to date, there is a consensus among experts that all persons parenting an affected child benefit from ongoing support and advocacy for various medical, educational and psychosocial issues that arise with children prenatally exposed to alcohol and other substances.

There is no evidence to date, but there is a consensus among experts that children with FAS and related effects benefit from the development of an Individualized Education Plan (IEP) tailored to meet the multiple cognitive, academic and psychosocial needs of these children, involving a range of collaborating professionals.

To date, there is no evidence on effective educational environments; however, there is a consensus among experts that the learning environment should be generally adjusted for children with FAS and related effects by establishing a calm and quiet environment with structure, routine and few distractions; low-enrolment classrooms, resource rooms or self-contained classroom placement; defined specific work and play areas; and work spaces that are clear and routines that vary little from day to day. Other elements contributing to a suitable environment include: use of explicit instructions and visual aids to reinforce class rules and activities; repetition, hands-on learning; modeling of desired behaviours; and a caring teacher.

While there is no evidence on effective educational practices to date, there is a consensus among experts that considerations for school content should generally involve an individualized curriculum with a focus on functional skills for independent living (such as problem solving, arithmetic, social interacting, and decision-making); developing realistic expectations of the child; behaviour management strategies that promote independence; adaptive living, social and communication skills; and role playing to teach logical consequences and appropriate behaviour.

7.3 Adolescent Interventions

There are almost no published studies of the effectiveness of intervention for this population. Consequently, only tentative conclusions on the effectiveness of various intervention options can be drawn.

7.3.1 Medical Issues

Children with FAS appear to go through puberty normally and at the normal age. Stratton et al. (eds.) (1996) reported that there do not appear to be any medical problems resulting from prenatal exposure during this period.

7.3.2 Psychoeducational and Social Issues

Many of the psychosocial problems emerging in childhood become more pronounced among adolescents exposed to alcohol *in utero*. Early gains are not maintained and it is often during this period that serious problems are encountered at home and at school.

A significant proportion of children with FAS have below average IQs (Steinhausen et al., 1993) with, of course, very large implications for educational intervention as well as programming in other domains. There is some indication from the literature on training people with non-alcohol-related intellectual deficits that cognitive-behavioural approaches are effective in bringing about improvements in the use of strategies for remembering and learning, self-control, and self-checking. Behavioural family therapy with parents and children with non-alcohol-related intellectual deficits have also had positive results that were maintained over time (Niccols, 1994). Whether any of these strategies can be applied effectively to children with FAS or related effects, and who have intellectual deficits, has not been tested.

As adolescents, many individuals with FAS have ongoing social and behavioural problems. The most compelling information to support this is the study by Streissguth and colleagues (1996) of over 400 clients with FAS and related effects who had been diagnosed at younger ages. The sample ranged in age from 3 to 51 years, but the majority were adolescents and young adults. The diagnosis of FAS or the partial syndrome was considered to be the primary disability, and what the authors termed "social" problems were viewed as the secondary disabilities.

Their findings showed that adolescents with FAS and related effects had high rates of secondary disabilities, including mental illness, substance abuse, trouble with the law, school failure, and homelessness. Mental health problems were the most common, being experienced by 94% of the participants. A disrupted school experience, including suspensions and expulsions, had been experienced by 43% of the individuals. These negative school experiences began very early for some individuals (e.g., being expelled from kindergarten due to disruptive behaviour). Difficulty with adaptive functions (e.g., failing to consider the consequences of actions, being unresponsive to social cues, lacking reciprocal friendships) is a hallmark of FAS, so it is not surprising that Streissguth (1997) reported that even those who did not have intellectual deficits repeatedly showed difficulties with adaptive living skills.

One of the paradoxical findings from Streissguth's 1996 study was that higher functioning individuals with FAS, as well as those diagnosed with FAS later in life, had equal or greater adjustment problems than those individuals who functioned at a more handicapped level, and those diagnosed earlier (i.e., before age six). Streissguth et al. (1996) speculated that the greater exposure to special education and other services that the more affected individuals had likely received helped with their transition to adult living, buffering them from the adverse circumstances experienced by the higher functioning children who had to navigate the transition to adulthood without special supports. In addition, children with the full syndrome are often physically different, which may lead to more accommodations being made for their challenging behaviour. It may also be that the negative behaviour of lower functioning FAS youth is more likely to be tolerated.

A major limitation of the Streissguth et al. (1996) study is the lack of control subjects. An ideal design would have matched these individuals with peers for age, education, IQ and living environment. The lack of controls makes it difficult to conclude that this high rate of social dysfunction is a direct consequence of prenatal alcohol exposure, rather than, for example, family variables.

Steinhausen et al. (1993) also presented data on a sample of 158 German young people with FAS and found that 63% of the individuals suffered from at least one psychiatric or medical disorder and that a number of these disorders, including emotional, sleep and attention-deficit and hyperactivity disorders, persisted over time

Also in Germany, Spohr and his colleagues (1994) reported that up to 50% of 44 adolescents they had followed longitudinally had emotional problems and 19% had behavioural problems, again underscoring the significant mental health needs of these individuals during adolescence. As with the other longitudinal studies cited, Spohr et al. (1994) did not include a control group, making it difficult to confidently attribute the problems to prenatal alcohol exposure rather than postnatal experiences.

Given the greater societal expectations placed on all persons during adolescence, there is reason to think that the stability in home life for alcohol-affected persons that seems to be important in earlier childhood is at least as important during this period (Streissguth, 1997).

At home and at school, these young people need assistance with problems related to socialization and communication, as well as tailored vocational counselling and job training (Phelps and Grabowski, 1992). To address problems of inappropriate sexual expression, families and schools need to give attention to information and training on sexuality, including birth control, for girls particularly (LaDue et al., 1992). Famy et al. (1998) suggest that substance abuse starts early in adolescence for many youth with FAS. These young people need to be considered at high risk for problematic substance use and should receive tailored information and programming on this issue. The involvement of knowledgeable mental health professionals and a parent support network can assist both the young person and their parents in dealing with the many issues associated with adolescence for those affected by prenatal alcohol exposure.

In discussing the circumstances of adolescents and adults with FAS, Streissguth and O'Malley (in press) note that the need for services is ongoing. They point out that families caring for those with FAS need appropriate support services before the situation gets out of control, and it is apparent that the need continues over the life-span of the individual. Ongoing services are particularly important with respect to sheltered living, job training, ongoing employment supervision, money and life management and positive role models (Streissguth and O'Malley, in press).

This range of services is currently only rarely available to persons with FAS. The situation is exacerbated in some communities because of a general lack of appreciation for the extent and nature of the problem. Kowalsky and Verhoef (1999), from a qualitative study in a northern community, reported that, among other issues, a lack of knowledge of FAS and denial of the problem on the part of both professionals and others in the community were barriers to the development of appropriate services.

7.3.3 Young Offender Issues

Recent studies have indicated that significant proportions of adolescents with FAS and related effects have early and repeated trouble with the legal system. For example, researchers in BC (Fast et al., 1999) studied youths remanded to a young offender assessment unit, to which the court sent those requiring psychiatric and psychological assessment. They found that, over a one-year period, 1% of the 287 youths had FAS and a total of 23.3% had alcohol-related effects (includes those with FAS). Only 3 of the 67 youths had been previously diagnosed. The types of crimes most frequently committed by individuals with alcohol-related effects were theft (43%), assault (39%), breach/failure to comply (43%), and vandalism/mischief (21%). There were no differences between young offenders with and without an alcohol-related-diagnosis in terms of the types or severity of the crimes committed.

There has traditionally been, and continues to be, an inadequate understanding and handling of young persons with FAS or related effects in the justice system. This is true both in terms of the legal system (e.g., FAS is not a recognized legal defense) and once they are incarcerated (e.g., no appropriate alternative treatment models have been developed; the need for specialized facilities has not been considered). The youth justice system generally needs to become more aware of the issues facing these young people, particularly their limited ability to account for and take responsibility for their actions.

There is a tendency for young offenders with FAS or related effects to be labeled as "model prisoners", because they often thrive in highly structured environments, such as correctional facilities. While there are no data to support this impression, it appears that when these youth are released (often receiving an "early release" for good behaviour), they do not have the skills necessary to function in an unstructured environment, resulting in a reportedly high rate of recidivism (Conry and Fast, 2000).

Conry et al. are in the process of developing a manual for use by court workers, including judges, to help them work more effectively with individuals with FAS and related effects before the courts. It is important to note that individuals with FAS and related effects may be victims, witnesses, or the accused in court proceedings.

7.3.4 Summary

Individuals with FAS and related effects usually experience increasing psychological and social difficulties in adolescence. Problems with substance abuse, sexual expression and criminal behaviour are typically first noticed during adolescence. Stability in the living environment continues to be important for these youth, and birth, adoptive and foster parents need continuing support. While educational interventions for these youth have not been studied for outcome, indications are that these young people, more than ever, need tailored educational programming at this point in their lives. Cognitive-behavioural and behavioural family therapies have shown promise in the general mental retardation literature; the extent to which they may prove useful for young people with FAS or related effects (especially those without intellectual deficit) is open to speculation at this point. While it is apparent that a disproportionate number of young offenders may have FAS or related effects, there is as yet no indication of the effectiveness of intervention for this population as none has been developed to date.

7.3.5 Best Practice Statements

While there is no evidence to date, there is a consensus among experts that adolescents with FAS and related effects benefit from assistance with basic socialization and communication skills as well as tailored vocational counselling and employment supervision, money management training, sexuality and birth control education, and drug education.

There is no evidence to date, but there is a consensus among experts that adolescents with FAS or related effects who become involved with substance abuse treatment, mental health or the correctional system, may benefit from tailored programming.

While there is no evidence to date, there is a consensus among experts that families caring for those with FAS and related effects benefit from appropriate professional services and mutual support groups that extend over the life-span of the person.

Although those with intellectual deficits due to prenatal alcohol exposure have not been studied specifically, there is some evidence that cognitive-behavioural and behavioural family therapies are effective in helping those with intellectual deficits to learn and maintain various basic living skills.

7.4 Adult Interventions

There are few published findings on issues concerning adults affected by FAS, and studies of the effectiveness of intervention for this population are still more sparse. Streissguth and her colleagues (1996) in Seattle have published virtually all of the extant literature. Most of their investigations have used relatively small client samples without using control groups, making it difficult to assess the relative contribution of prenatal alcohol exposure and various postnatal social factors such as lack of support services, late diagnosis, poverty and family dysfunction to the development of problems. Consequently, only very tentative conclusions on the effectiveness of adult intervention can be drawn.

7.4.1 Medical Issues

Streissguth et al. (1996) found a high level of mental health and substance abuse problems among their mixed sample of 415 adolescents and adults. Famy et al. (1998) also found high rates of substance dependence and depression among a small sample of adults with FAS and related effects. A majority of the sample of 158 young people with FAS being followed by Steinhausen et al. (1993) in Germany was, at the time, showing long-term psychiatric problems that the author suggested would likely persist into adulthood.

7.4.2 Psychoeducational and Social Issues

With the "first generation" of FAS-diagnosed persons now moving through adulthood, the enduring nature of FAS is becoming increasingly clear. Most persons with FAS and related effects are not able to live totally independent lives at any point (LaDue et al., 1992).

CNS damage results in a patchwork of competencies and limitations that vary between individuals. Typically, however, the adult with FAS continues to have problems with impulsivity, attention, poor judgment, difficulty in recognizing and setting boundaries, social-relationship problems, decision-making and higher-order skills, such as time and money management (LaDue et al., 1992).

These problems often result in adults with FAS having difficulty with independent living and employment. Streissguth et al. (1996) found that 83% of their sample of 90 adults did not live independently. They also found that half the sample of affected adults had never held a job for more than a year. Only 8% of the adult sample was living independently and not experiencing employment problems. Areas of daily life that this sample found most challenging were managing money, obtaining medical care and social services, handling interpersonal relationships, and grocery shopping. Rutman et al. (2000) reported on interviews with a sample of adults with FAS and individuals supporting them in BC. Participants suggested a number of strategies for independent living, including learning about FAS and its implications, developing support systems, keeping detailed schedules and lists of what needs to be done each day, and taking parenting courses.

From another case investigation of a sample of 61 predominantly Native Americans from 12 to 40 years of age diagnosed with FAS or related effects, Streissguth et al. (1988) concluded that adults and older adolescents require well structured work and living opportunities that demand broad community commitment to this issue.

Streissguth et al. (1996) studied factors associated with independent living after the age of 21 years. Those with an IQ of less than 70, were unable to live independently as adults. Similarly, those whose performance IQ was greater than verbal IQ by 15 points were less likely to live independently. Although those with an IQ of less than 70 were all living in dependent situations, they had lower rates of alcohol and drug problems, disrupted school experience, trouble with the law and confinement. An IQ of more than 70 is associated with better outcomes and independent living.

Hess and Nieman (1997) recommend a range of non-institutional living options be made available for adults with FAS for the duration of their lives, to allow them to experiment with greater levels of independence (if and when a person is able to take them on), and to also provide them with backup support when periods of acute crisis arise. They assert that the cost of housing an individual within this type of continuum should decline over time as the person assumes greater independence.

Streissguth et al. (1996) reported on problems with employment. Two risk factors for employment are being FAS and having a low IQ. Employment-related supports, identified by a sample of individuals in BC with FAS, and those supporting them, included specifically designed job preparation programs, having structure yet flexibility in the work environment, having an informed and understanding supervisor, and having an on-the-job mentor or coach (Rutman et al., 2000).

Many of the mental health, housing and employment interventions or services required by adults with FAS are not readily accessed in a community or do not exist. It appears extremely important that the affected adult have the active and ongoing support of a case manager to help navigate the various services he or she will likely require regardless of IQ (LaDue et al, 1992). Streissguth and colleagues (1997) have employed a paraprofessional advocacy model for a number of years, using parents, relatives or someone from the community as advocates. Their role is to serve as mediators between the person with FAS and their environment, assisting them in accessing needed services, and helping all concerned develop realistic expectations (Streissguth, 1997). The effectiveness of this model with adults has not yet been determined.

Because of the many issues facing adults with FAS or related effects, for these individuals themselves to become parents can be problematic and children may be at-risk. There is some indication that those with more difficult childhood experiences are more likely to have their own children. Comparing a group of older adolescents and young adults with FAS or related effects who were parents with others who weren't, Porter et al. (1997) found that those who were parents experienced more homelessness, more running away from home and more time in unstable and non-nurturing living environments while growing up. Although the data are correlational, it does provide further support for the contention that a safe, stable living environment is critically important for affected persons. Individuals in BC with FAS and those supporting them reported the following as important for people with FAS: routines and schedules; reminder list of daily activities; learning how to provide discipline; learning coping and parenting strategies; and having patience (Rutman et al., 2000).

For a variety of reasons, (e.g., self-esteem issues, problems with adaptive functioning, having at least one parent having had alcohol problems) persons with FAS are at increased risk for alcohol problems. Although there are currently no models to refer to, several case studies of alcohol-dependent persons with FAS conclude that substance abuse treatment needs to be organized differently for affected individuals (Streissguth et al., 1995). The general thrust of the recommendations arising from their investigation is that affected persons need to be identified at intake, referred for assessment and diagnosis, and require more support throughout the process, including more individualized contact with counsellors, more practical relapse prevention advice, and active assistance with such matters as housing, job training, social skills training and anger management.

7.4.3 Correctional Issues

Forty-two per cent of the adults in the Streissguth et al. (1996) sample had been incarcerated. In a review of FAS and adult correctional issues, Boland et al. (1998) noted that the behaviour patterns that characterize individuals with FAS, namely impulsivity, poor judgment, and difficulty understanding consequences, place them at high risk of engaging in and being apprehended for criminal activities.

Boland et al.(1998) recommended improved access to diagnostic services for FAS within the correctional system. The authors noted the difficulties involved in making a diagnosis in adults and in accessing medical personnel with expertise in the area of dysmorphology within the prison system. They suggest that a screening instrument for identifying persons with FAS be developed or adopted for use in Canadian federal prisons.

In light of the central nervous system dysfunction of those exposed to alcohol prenatally, Boland et al. (1998) suggest that intake assessment and various programs (e.g., anger management, life skills and substance abuse, pre-release) need to be simplified, with assessment results and other information also modified for the inmate. Other suggestions include increased staff training on issues related to FAS and appointing an advocate for those with FAS in an institution. At this point, the effectiveness of particular interventions for incarcerated persons with FAS or related effects has not been empirically studied.

7.4.4 Summary

Adults with FAS continue to experience difficulties in a number of life areas that make independent living a challenge. While evidence is quite limited, ongoing family support, advocacy and/or case management, with particular attention given to special living arrangements and early job training, appear very important in helping the affected person meet these challenges. Substance abuse and mental health treatment are often necessary. Because of ongoing difficulties with memory, attention and acting impulsively, those who work with this population suggest these services as well as correctional services need to be modified. While empirical study remains to be undertaken, suggested modifications include more individualized contact with counsellors, simplifying and giving more active assistance and repetition with instructions and tasks, and tailoring of such programs as anger management and relapse prevention.

7.4.5 Best Practice Statements

While there is no evidence to date, there is a consensus among experts supporting continuing advocacy or case management to help the adult affected by prenatal alcohol exposure to adequately deal with the many challenges of adult life.

While there is no evidence to date, there is a consensus among experts that frequently required programs, such as substance abuse treatment, employment training, mental health therapy, and correctional services, need to be modified to be of benefit.

7.5 Interventions for Children Affected by Other Drug Use During Pregnancy

7.5.1 Early Childhood

Most studies regarding the effects of other drug use did not control for the use of alcohol; children who are exposed to multiple drugs are likely to be exposed to alcohol as well (see also section 6.7). Therefore it is difficult to unravel the effects of individual substances. There is no consistent pattern that describes children prenatally exposed to drugs other than alcohol. Not all children who experience prenatal exposure show impairment and those that do vary considerably in the type and severity of effects (Olson and Burgess, 1997). Lester et al. (1996) point out that the effects of prenatal substance exposure generally tend to be subtle, rather than pronounced.

Olson and Burgess (1997) in summarizing adverse effects associated with prenatal exposure to substances other than alcohol, conclude that exposure "is not typically associated with major developmental disabilities or a specific behavioural syndrome". They further note that when they do occur, effects for drugs other than alcohol have been generally found in areas of arousal modulation, activity level and attention regulation. More specifically, prenatal cocaine use has been associated with impairment of early learning and emotional responsivity; cannabis use, with cognitive development; opiate use, with motor regulation and lack of coordination; multiple substance use, with low cognitive or developmental scores, disorganized play and insecure attachment patterns (Olson and Burgess, 1997).

Beyond the first few weeks of life, experimental studies have generally been unable to distinguish the effects of prenatal exposure from those that may be attributed to the child's postnatal environment (Cole, 1995). The effects of prenatal alcohol exposure may also be difficult to distinguish from exposure to other substances during the early weeks, so recommended interventions at the infancy and early childhood levels are often intended to serve children affected by either alcohol or other substances or both (Olson and Burgess, 1997).

At any rate, as is the case with interventions for alcohol-exposed children, there is little empirically based evidence for particular interventions for children exposed to other drugs prenatally. Nevertheless, expert consensus points to a continuum of support services to address the multiple needs of substance-exposed children and their families.

Repeated fetal exposure to drugs producing physical dependence, most commonly opiates (e.g., heroin and methadone), barbiturates and alcohol may lead to fetal drug dependence and after birth, to Neonatal Abstinence Syndrome (NAS), the withdrawal of the drug from the newborn. Characteristics of a child experiencing NAS include tremour, irritability, hypertonicity, high-pitched cry, vomiting and diarrhoea, respiratory distress, sneezing, fever, poor sucking, and rarely, convulsions (Theis et al., 1997). These symptoms will differ depending on the substance(s) used, and are usually observed within 48 to 72 hours of birth and last 2 to 8 weeks (Poulsen, 1995). Comfort measures such as swaddling, holding and reducing stimulation may provide sufficient intervention if symptoms are mild (Theis et al., 1997). Pharmacological treatment is recommended for more severe instances of NAS. In their review of efficacy studies for the more commonly used pharmacological treatments (i.e., phenobarbital, paregoric and diazepam), Theis et al. (1997) concluded that diazepam appeared to be less effective in treating NAS than the other two drugs; however, other conclusions were limited by the generally weak study designs. While cocaine or its metabolites will remain in the newborn and may continue to have a toxic effect, it does not produce a typical neonatal abstinence syndrome.

Because there is no typical profile of a substance exposed child, each child needs an individual medical and psychosocial assessment by a multidisciplinary team (Sinclair, 1998). Based on the assessment, referral to interventions by specialists and case coordination among the various services may be required. As mentioned in the previous discussion on early intervention for children exposed to alcohol, early support of the mother, family and child are strongly recommended to ensure that they continue to receive contact and care after leaving the hospital. If a link has not already been made, Thompson (1993) stresses the importance of intervention immediately on the birth of the child to increase the likelihood of a lasting relationship between the family and service providers. The mother serves as the gatekeeper for the child's access to services, so early support of the mother and family is crucial (Kandall, 1993). As the chair of a consensus panel for the US government, Kandall (1993) recommends that this include access to appropriate substance abuse treatment, mental health and family counselling, parenting education, job training, and housing assistance, rendered in a culturally and linguistically appropriate manner. Smith et al., (1995) describe a peer mentoring approach for new mothers with substance-use problems, using mothers who have shown success in child rearing. Similar to the Seattle Birth to Three Program (Ernst et al., 1999), these mentors work under professional supervision and help the family access health, social, literacy and job training services. Various other outpatient bridging services, specialized infant development and therapeutic child care programs are often recommended, though these interventions have not yet been evaluated for use with substance-exposed children (Olson and Burgess, 1997).

Field et al. (1998) studied the effectiveness of a four-month intervention featuring treatment, schooling, relaxation therapy, vocational training and parenting classes as well as child care, with a sample of 126 young mothers (16 to 21 years of age). At the 3-, 6- and 12-month follow-up, mothers and children showed significant gains over the control group. Mothers receiving the intervention showed a lower incidence of continued drug use and repeat pregnancy, and a greater number continued school or were placed in a job. The infants of these mothers showed superior development scores, fewer pediatric complications and greater head circumference.

While birth may be the earliest point of intervention in some cases, it is preferable to intervene as early as possible in a pregnancy. Using a quasi-experimental study design, O'Donnell and colleagues (1997) tested the Infant Care Project, a comprehensive and continuous blend of services for mothers using cocaine during pregnancy and their infants. The program was set in the hospital and began working with mothers during pregnancy. Through this period, program elements included assessment, support group, and mother-child attachment activities. On birth of the child, assessments were completed, child development activities were initiated and women were encouraged to participate in the support group. The support group was termed a "predecision" group that provided participants a non-judgmental setting to consider their substance abuse. Sponsors felt this element was crucial to retaining contact with women who were not ready to commit to treatment. Evaluation data indicate that participation in the project was associated with improved compliance with prenatal care, reduced drug use during pregnancy, improved obstetrical outcomes, and an increased likelihood of the mother retaining custody of her child at 12 months following birth. There was no difference in the child development outcomes between the study and comparison group at 12 months.

Substance-using mothers and their families are not a homogeneous group, but they often have a number of needs that should be served in a coordinated fashion (Thompson, 1993). Many experts recommend a comprehensive approach to serving the needs of both the mother and the family, as with the "one-stop shopping" model served by a multidisciplinary team through which both the mother's substance use and the child's developmental needs are addressed. Along with alcohol, crack cocaine is a primary drug of choice for clients of Breaking the Cycle, a comprehensive program in Toronto.

The program has collected data suggesting benefits to both mother and child participants (Paquet, 1998). In smaller communities where this model may not be feasible, these services need to be provided by several agencies that carefully coordinate with one another (Kandall, 1993).

Substance-involved parents may give less priority to parenting. Consequently, parenting education may need to be both innovative and intensive. With parents in methadone treatment, Catalano et al. (1997) reported some positive findings from a well-designed study of the effects of home-based case management services and systematic group training in relapse prevention and parenting skills. Case managers helped parents to secure needed services and worked with parents to implement learned parenting skills at home. The training component consisted of 32 sessions, amounting to two 90-minute sessions a week. A variety of small gifts were used to encourage attendance and completion of homework. Transportation and child care were provided as needed. Fifty-one per cent of those assigned to the experimental group attended at least half of the sessions.

At follow up, experimental subjects were holding significantly more family meetings to discuss various topics and showed significantly less current opiate use, suggesting that an intensive and comprehensive parenting program may be a useful intervention for parents in methadone treatment and their children.

In their review of early interventions, Olson and Burgess (1997) describe a study of a home-based intervention with a relatively small sample of substance-abusing women using a randomized clinical trial. The women were primarily single, low-income, non-high school graduates of African-American origin. The intervention included primary care in a multidisciplinary clinic and bi-weekly home visits by a nurse beginning before delivery and continuing until the child was 18 months. The intervention mothers showed marginally positive results on self-reported abstinence, compliance with appointments, providing more emotional responsiveness, and more opportunities for developmental stimulation to their children.

Children prenatally exposed to substances may experience more adversity due to neglect, abuse, violence and inadequate parenting skills (Mayes and Carroll, 1996). In some cases, it may be necessary for child welfare services to become involved with a family. Kandall's (1993) consensus panel notes that prenatal drug use or a positive drug test should not be considered an adequate reason, in and of itself, to refer an infant to child welfare services. Neither should the mother's ongoing substance use, by itself, be a criterion for removing a child from the home. Occasional relapse should be anticipated as a part of the recovery process and as such should not be the sole criterion for removing the infant from the home. Rather, the decision to remove a child from the home should be made if the child is endangered or the parents cannot adequately provide for the child's health and safety (Kandall, 1993).

In the US, foster parent training and specialized foster homes, and transitional group care settings for substance-exposed children have been established, although at this time, they have not been subjected to an evaluation.

7.5.2 Later Childhood

Head Start programs for children at-risk may be in a position to provide tailored interventions for substance-exposed children. A study by Sinclair (1998) suggests that prenatal substance exposure may predict a need for special education kindergarten placement. When compared with children with no record of substance exposure, substance-exposed children were rated as having a higher prevalence of emotional and behavioral disorders, medical and academic problems, and speech and language deficits and were more likely to be referred to special education kindergarten. Although a comparison group was used in this study, there is no discussion of the differences between the two groups at baseline (for example, with respect to stability of home life) and how the differences were controlled. Consequently, postnatal environmental factors such as child abuse and neglect, poverty, violence, and continued parental substance abuse may have contributed to the observed outcomes. Sinclair concluded that these children need individually tailored educational programs rather than a program designed for "drug exposed" children; however, there is not yet any empirical evidence to support particular enhancements to Head Start programs.

Without providing outcome data, Kne et al. (1994) reported on a K-3 program in California for drug-exposed children. Noting that these children do not differ from other children in intelligence and neurological development, a premise of the program was that it was not necessary to separate these children from their regular classroom through the special education process. The authors contended that behaviour problems sometimes seen in these children are best addressed through programs that serve all children with behaviour problems, thereby avoiding labelling. In the estimation of the authors, home visits were crucial to successful intervention, because of the need for cooperation from the parents. Other features of the intervention were partnerships with appropriate medical and educational specialists, mentoring by advocates, and a school-based learning centre with a positive, predictable climate.

There is some indication that CNS dysfunction may become more obvious as the infant moves into early childhood; consequently, the longer-term impact of prenatal exposure to other substances is still very much in question (Olson and Burgess, 1997). For example, Fried (1996) in his prospective study of children exposed to marijuana prenatally, reported verbal deficits at age 4. However, by 6 years, the verbal deficits observed at 4 years were no longer present. Fried suggested that the external environment, including school attendance, may help to ameliorate these early deficits (Fried, 1996). While there are no data to support this impression, there appears to be a need for greater intervention attention given to children affected by prenatal inhalant abuse in some northern and isolated communities in this country.

7.5.3 Summary

While the child developmental effects of prenatal use of substances other than alcohol and inhalants tend to be subtle, they are reasonably well defined and can interfere with normal development. Consequently, many of the interventions that are recommended for persons affected by prenatal alcohol exposure apply to children affected by other substances as well.

Although empirical evidence is limited, it appears that intervening at birth (or before) presents the best prospect for ameliorating the effects of prenatal substance use. Encouraging the mother and partner, if appropriate, to address their substance use while engaging them in caring for their child can begin in the hospital and continue in the community through "one-stop" services or the collaboration of several agencies. Services need to be comprehensive, addressing the range of issues facing these mothers and families, including vocational and housing issues. Programs that continue to support mothers and their families through intensive case management or mentoring approaches tend to result in improved outcomes for mothers, while the evidence for improved outcomes for children is more limited at this point.

7.5.4 Best Practice Statements

There is some evidence that comfort measures (i.e., swaddling and holding) are effective interventions for mild cases of Neonatal Abstinence Syndrome, while pharmacological treatments such as phenobarbital and paregoric can support withdrawal management in more severe cases.

There is some evidence, and a consensus among experts indicating that support of the mother immediately following birth with a comprehensive range of services (such as mental health, substance abuse treatment, family counselling, parenting education, schooling, job training and housing assistance) leads to improved outcomes for mother and child.

There is some evidence, and a consensus among experts pointing to intensive case management, mentoring, home visits and single points of access, as effective vehicles for the delivery of services.

8. Summary of Best Practice Statements

Primary Prevention

There is some evidence that measures to limit the availability of alcohol, such as bans on sales and importation that are broadly supported by the community, or price increases, can reduce heavy alcohol use by pregnant women at least in the short-term.

There is some evidence to support warning labels and posters as a means of increasing awareness and effecting short-term behaviour change among low-risk women. However, women who drink heavily during pregnancy do not appear to be affected by warning labels.

There is some evidence to support multi-component community-wide initiatives as a means of increasing awareness generally, reducing consumption for pregnant women, and promoting referrals.

There is moderate evidence to support the use of life-skills-based and multi-component school-community substance use prevention programs as a means of preventing or delaying substance use among youth and, in turn, reducing substance use problems among adults.

Secondary Prevention

There is a consensus among experts to support routine screening of pregnant women for use of alcohol and other substances in various settings, including justice, housing and health settings.

There is moderate evidence to support the use of the T-ACE and TWEAK, and some evidence to support the use of CAGE and AUDIT alcohol dependence instruments in a supportive milieu to identify women who would benefit from intervention for their alcohol use during pregnancy.

There is some evidence and a consensus among experts to support selective use of bio-markers by physicians, with the informed consent of the client, as a follow-up to a written screen.

There is good evidence that brief interventions in prenatal settings, based on cognitive-behavioural principles, are effective low-cost means of helping pregnant women with early-stage alcohol problems to reduce or eliminate alcohol use during pregnancy.

There is some evidence to support the effectiveness of drug education programs in reducing substance use among pregnant adolescents attending prenatal clinics.

There is some evidence and a consensus among experts that training can be effective in helping physicians and other professionals work with women who have substance use problems.

Tertiary Prevention

There is moderate evidence and a consensus among experts that combining prenatal care with other services, including substance abuse treatment, shows positive outcomes for women with substance use problems and their newborn child.

There is moderate evidence and a consensus among experts that gender-specific substance abuse treatment is more effective for women than programs serving both men and women.

There is some evidence and a consensus among experts that treatment services employing a respectful, flexible, culturally appropriate and women-centred approach that is open to intermediary harm reduction goals, based on client circumstances, are effective in engaging and retaining women in supportive programming and in improving the quality of their lives.

There is some evidence and a consensus among experts that services with a single point of access addressing the range of social and health needs of pregnant women with substance use problems (e.g., assistance with transportation and child care, education, vocational training, job placement, housing, getting food, income support, and help in accessing health care and mental health services), through collaboration between relevant service providers, are effective in engaging and retaining women in treatment.

There is strong evidence that intensive case management or coordination services that advocate for women can be effective in promoting family planning, access to substance abuse treatment, retention in treatment, reduced consumption and connections to community services for high-risk pregnant women.

There is some evidence that a contingency management approach is effective in reducing cocaine use and increasing attention to prenatal care among cocaine-dependent women.

There is moderate evidence that providing Methadone Maintenance Therapy (MMT) in the context of comprehensive care has a positive impact on the health of mothers and birth outcomes for mothers who are opiate-dependent. Priority access to MMT for pregnant women and program components that address barriers to treatment should be considered in program design. Guidelines for methadone dosage and regimen should take into account changes in methadone metabolism that may occur in the later stages of pregnancy.

There is no evidence to support the use of punitive measures, such as mandated treatment, as being effective in improving maternal and fetal health. A consensus among experts suggests that such measures deter pregnant women from seeking needed services.

Identification of FAS and Related Effects

There is some evidence that prenatal screening for FAS is most effective when initiated by routine, collaborative screening of mothers during prenatal care.

There is a consensus among experts that the availability of diagnostic services can be enhanced through mechanisms such as specialized training, consultation and support, telemedicine, and traveling clinics.

There is a consensus among experts that, in the presence of particular maternal characteristics (including lack of prenatal care, previous unexplained fetal demise, repeated spontaneous abortion, severe mood swings and precipitous labour), or infant attributes (including prematurity, unexplained intra-uterine growth retardation, neuro-behavioural abnormalities, urogenital anomalies, myocardial infarction and blood flow restriction), selective screening for maternal substance use by taking a detailed maternal history in a supportive atmosphere can be effective in identifying children affected by prenatal use of substances other than alcohol.

Infancy and Early Childhood Interventions

There is a consensus among experts to support the use of a professional, multidisciplinary team to address the range of complex health needs of affected children.

There is some evidence to suggest that a longer-term, stable living environment contributes to more positive outcomes for children affected by alcohol in utero. This may be facilitated by family-centred substance abuse treatment, respite care and other support services, and FAS-specific information and training for birth, foster and adoptive parents.

There is a consensus among experts indicating that child-care programs for children affected by prenatal alcohol exposure employing a low staff-child ratio, following structured routines and regulating the amount of stimulation received by the child may be more effective.

There is some evidence that services offering a single point of access, combining services for the mother with attention to the developmental needs of the child, improve outcomes for the child.

There is a consensus among experts that all persons parenting affected children benefit from and value a range of services to support their parenting of children with FAS and related effects.

There is some evidence from animal studies and studies of children experiencing developmental delay due to other causes suggesting that early educational interventions may contribute to improved outcomes for children affected by prenatal alcohol use, at least in the short-term.

Later Childhood Interventions

While there is no evidence to date, there is a consensus among experts that all persons parenting an affected child benefit from ongoing support and advocacy for various medical, educational and psychosocial issues that arise with children prenatally exposed to alcohol and other substances.

There is no evidence to date, but there is a consensus among experts that children with FAS and related effects benefit from the development of an Individualized Education Plan (IEP) tailored to meet the multiple cognitive, academic and psychosocial needs of these children, involving a range of collaborating professionals.

To date, there is no evidence on effective educational environments; however, there is a consensus among experts that the learning environment should be generally adjusted for children with FAS and related effects by establishing a calm and quiet environment with structure, routine and few distractions; low-enrolment classrooms, resource rooms or self-contained classroom placement; defined specific work and play areas; and work spaces that are clear and routines that vary little from day to day. Other elements contributing to a suitable environment include: use of explicit instructions and visual aids to reinforce class rules and activities; repetition, hands-on learning; modeling of desired behaviours; and a caring teacher.

While there is no evidence on effective educational practices to date, there is a consensus among experts that considerations for school content should generally involve an individualized curriculum with a focus on functional skills for independent living (such as problem solving, *arithmetic, social interacting, and decision-making); developing realistic expectations of the child; behaviour management strategies that promote independence; adaptive living, social and communication skills; and role playing to teach logical consequences and appropriate behaviour.*

Adolescent Interventions

While there is no evidence to date, there is a consensus among experts that adolescents with FAS and related effects benefit from assistance with basic socialization and communication skills as well as tailored vocational counselling and employment supervision, money management training, sexuality and birth control education, and drug education.

There is no evidence to date, but there is a consensus among experts that adolescents with FAS or related effects who become involved with substance abuse treatment, mental health or the correctional system, may benefit from tailored programming.

While there is no evidence to date, there is a consensus among experts that families caring for those with FAS and related effects benefit from appropriate professional services and mutual support groups that extend over the life-span of the person.

Although those with intellectual deficits due to prenatal alcohol exposure have not been studied specifically, there is some evidence that cognitive-behavioural and behavioural family therapies are effective in helping those with intellectual deficits to learn and maintain various basic living skills.

Adult Interventions

While there is no evidence to date, there is a consensus among experts supporting continuing advocacy or case management to help the adult affected by prenatal alcohol exposure to adequately deal with the many challenges of adult life.

While there is no evidence to date, there is a consensus among experts that frequently required programs, such as substance abuse treatment, employment training, mental health therapy, and correctional services, need to be modified to be of benefit.

Interventions for Children Affected by Other Drug Use During Pregnancy

There is some evidence that comfort measures (i.e., swaddling and holding) are effective interventions for mild cases of Neonatal Abstinence Syndrome, while pharmacological treatments such as phenobarbital and paregoric can support withdrawal management in more severe cases.

There is some evidence, and a consensus among experts indicating that support of the mother immediately following birth with a comprehensive range of services (such as mental health, substance abuse treatment, family counselling, parenting education, schooling, job training and housing assistance) leads to improved outcomes for mother and child.

There is some evidence, and a consensus among experts pointing to intensive case management, mentoring, home visits and single points of access, as effective vehicles for the delivery of services.

Steering Committee Members

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